CONTINUED OCCUPATIONAL THERAPY FOR STROKE PATIENTS AFTER HOSPITAL DISCHARGE

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DECLARATION

I declare that the work presented in this thesis is the result of my own investigations except where due reference is made to other authors in the text.

I also declare that this thesis has not been, nor is currently being submitted in candidature for any other degree.

Signed.....

ABSTRACT

There is a need for continuing support and intervention for stroke patients after in-patient rehabilitation. A randomized controlled trial was therefore conducted with the aim of evaluating the influence of continued rehabilitative intervention by an occupational therapist to stroke patients after their discharge from a stroke unit. One hundred and ten patients were recruited and randomly allocated to either a control or intervention group. Those in the intervention group were reviewed regularly by an occupational therapist (at 2, 8, 16 and 24 weeks following discharge) and appropriate therapeutic interventions were carried out as needed. The control patients received no special intervention or follow-up. Outcome of the two groups was compared at one year post stroke, using measures of activities of daily living, extended activities of daily living, mood, overall quality of life and use of services. Although there were few significant differences between the two groups at one year in terms of activities of daily living, extended activities of daily living, mood, overall quality of life and use of services, the number of stair rails and toilet aids received by the intervention group was significantly more ($p=0.05$) and the number of readmissions less ($p=0.03$). The provision of a follow-up service may benefit the patients by addressing any problems they have post discharge, ensuring they receive all necessary aids and maintaining them at home and reducing the need for readmissions to hospital.

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NOMENCLATURE

ADL	Activities of Daily Living
CT	Computerized Tomography
df	Degrees of Freedom
EADL	Extended Activities of Daily Living
FAD	McMaster Family Assessment Device
GP	General Practitioner
GDS	Geriatric Depression Scale
MMSE	Mini-Mental State Examination
NHP	Nottingham Health Profile
NHS	National Health Service
OT	Occupational Therapy/ist
PNF	Proprioceptive Neuromuscular Facilitation
PT	Physiotherapy/ist
RCT	Randomized Controlled Trial
SIP	Sickness Impact Profile
ST	Speech Therapy/ist
t	T-Test
TIA	Transient Ischaemic Attack
UHW	University Hospital of Wales
UK	United Kingdom
USA	United States of America
WHO	World Health Organisation
X^2	Chi-square Test
z	Mann-Whitney Test

CHAPTER 1.

INTRODUCTION

1. INTRODUCTION.

Stroke is one of the three most common causes of death along with cancer and heart disease in the United Kingdom (NHS Management Executive 1992), Australia (Christie 1982) and in the western world (Woodrow et al 1991). Every year some 110,000 people in the United Kingdom (population 56.5 million) have a stroke (Wade 1988a) and approximately 500,000 persons in the United States (population 238.5 million) suffer a stroke (Coletta and Murphy 1992).

Stroke is often caused by a thrombosis and haemorrhage, causing a lack of blood to the brain (Woodrow et al 1991). A stroke is usually manifested in a paralysis of the side of the body opposite the damaged side of the brain. It is a complex and uncertain condition that potentially disrupts all aspects of motor, sensory, language, cognitive and social functions (Falconer et al 1993). The severity of a stroke may be measured in terms of its biological effects, the impairments, disabilities, handicaps and the burden on society that these produce (Ebrahim 1990).

A major risk factor for stroke is age. After the age of 55 the risk of having a stroke doubles with each decade (Allen et al 1988). Demographic trends indicate an

increase in life expectancy and a 30% increase in those over 75 years of age leading to a 25% increase in the incidence of stroke by the year 2022 (NHS Management Executive 1992).

Rehabilitation forms a major part of the management of patients following stroke. It involves the restoration of patients to their fullest possible physical, mental and social capability (Langton Hewer 1990). The occupational therapist is one of the members of the rehabilitation team.

Various studies looking at the outcome of patients following a stroke have been carried out. Some have concentrated on the benefits of rehabilitation and the most suitable venue for it. For example, Garraway et al (1980a) conducted a controlled trial, looking at the management of acute stroke in the elderly in stroke units compared with those in medical units, and report a significantly higher proportion of patients discharged from the stroke unit as being assessed as independent compared with patients discharged from medical units. Such studies suggest that most rehabilitation following stroke concentrates on the acute phase and on the recovery of motor function and independence in activities of daily living (Corr and Bayer 1992).

Occupational therapy for stroke patients tends to concentrate on maximising functional independence in daily living requirements prior to hospital discharge and instrumental activities of daily living (for example, food preparation, shopping and cooking); restoration of personal and social activities and of leisure pursuits are given much less attention (Smith et al 1982).

Other studies have concentrated on the residual problems some time after the stroke. Garraway et al (1980b), in a follow-up trial to the above research, showed that the improvement in the functional outcome that had been achieved through establishing a stroke unit at the time of discharge from hospital had disappeared by one year. Garraway et al (1980b) suggest that several factors may have influenced these findings, including the over protection by the families of patients who have been treated in stroke units.

The view that patients' social functioning after discharge is poor has been shared by many. Even patients whose physical disability has ceased to be a serious obstacle do not necessarily return to a normal social life (Labi et al 1980, Christie 1982 and Niemi et al 1988) and the need for greater emphasis on psychosocial support in the after-care of stroke patients has been stressed (Ahlsio et al 1984 and Dennis and Warlow 1987). Geddes and Chamberlain

(1992) noted that a year post stroke many patients were unwell, anxious, poorly motivated and lacking in confidence. They also noted poor economic status, inappropriate housing, lack of opportunities for socializing, all of which can place greater burden on carers.

It was decided to conduct a follow-up audit of patients in Cardiff to establish if these patients are similar to those in other studies. The patients studied were consecutive discharges, during a 6 month period, from a 20 bedded stroke unit (Corr and Bayer 1992). Each patient was visited at least 6 months and not more than 12 months after discharge. During the visit information was collected on the use of health and social services and day-to-day functioning. The results showed that levels of dependency recorded at discharge tended to persist or worsen over subsequent 7 to 12 months and very few patients returned to any domestic, leisure or outdoor activities once they were back in the community. Those in residential care were especially disadvantaged and contact with health and social services was minimal. The results show that the long-term outcome in terms of instrumental activities of daily living and social functioning of many stroke patients is very poor (Corr and Bayer 1992).

These findings are similar to other studies and suggest that there is considerable need for continuing support and intervention for stroke patients after in-hospital rehabilitation. Concentration of rehabilitation services solely on the acute treatment phase therefore seems inadequate and longer-term support continuing after hospital discharge is needed (Corr and Bayer 1992). Without such continuing support and rehabilitative intervention after hospital discharge, severely impaired social functioning may be almost inevitable (Corr and Bayer 1992).

Further studies are needed to determine the impact of continuing occupational therapy input after stroke patients have been discharged from inpatient rehabilitation back into the community (Corr and Bayer 1992). It was decided to consider carrying out some research in South Glamorgan to address the problem of poor social functioning at follow-up.

There are two stroke units in South Glamorgan Health Authority, one in the University Hospital of Wales (UHW) (which was in St David's Hospital until September 1991) and one in Sully Hospital. These have 32 beds and 18 beds respectively. The total number of patients admitted during 1990 was 195 in St David's and 77 in Sully. At present following discharge there is no formal policy for

reviewing patients or providing further rehabilitation. There are two day hospitals in the area and some patients are referred to this service following discharge. Others are referred to the community physiotherapist and/or community occupational therapist. As there are no set guidelines or criteria for referral to these services, the follow-up services available are disjointed. This appeared an appropriate area of stroke care to research.

1.1 PURPOSE.

The aim of the research is to investigate the influence of rehabilitative intervention by an occupational therapist on the long term outcome of stroke patients following discharge from stroke units.

The objectives are:

- to conduct a randomized controlled trial allocating patients to a control or intervention group;
- to provide regular occupational therapy to the intervention group, as appropriate;
- to compare functional levels in activities of daily living, social functioning, mood, use of services, quality of life and if appropriate, carers' burden, of all patients in the control group with those in the intervention group one year post stroke;

- to evaluate continued occupational therapy for stroke patients after hospital discharge from a stroke unit.

CHAPTER 2.

LITERATURE REVIEW

2.1 STROKE

2.2 REHABILITATION

2.3 OCCUPATIONAL THERAPY

2.1. STROKE.

2.1.1 DEFINITION.

Aho et al (1980) on behalf of the World Health Organisation give the following definition of stroke: "Rapidly developed clinical signs of focal (or global) disturbance of cerebral function lasting more than 24 hours or leading to earlier death, with no apparent cause other than a vascular lesion" (Aho et al 1980:p113). Acute events originating from head injury or neoplasm as well as those in which the signs and symptoms of the episode disappear within a short period of time (transient ischaemic attacks) are excluded from the formal definition of stroke (Office of Health Economics 1988).

Cerebrovascular accident or stroke is caused by an interruption of the blood supply to the brain as a result of infarction (thrombus or embolus) or haemorrhage (cerebral or subarachnoid) (Woodrow et al 1991). Cerebral infarction is the predominant form of stroke, accounting for between three-quarters and four-fifths of all cases (Office of Health Economics 1988). Hypertension is the main cause of primary intracerebral haemorrhage, and the rupture of an intracranial aneurysm or arteriovenous malfunction are the commonest causes of subarachnoid haemorrhage (Warlow 1987).

The extent of the stroke depends on the site and size of the lesion (Warlow 1987). The severity of a stroke may be measured in terms of its biological effects, the impairments, disabilities, handicaps, and burden on society that these produce (Ebrahim 1990). The range of lesions which may occur, can result in virtually limitless permutations and combinations of symptoms (Held 1975 and Falconer et al 1993). The symptoms may include hemiplegia, sensory disturbances, perceptual dysfunction, personality and intellectual changes and a range of speech and associated language disorders (Woodrow 1991 and Falconer et al 1993). A stroke can be very mild, with only a slight speech disturbance or weakness, or it can result in death (Woodrow et al 1991). The nature of functional loss as well as the extent of disability, the speed of progression from the onset of symptoms and whether or not consciousness is lost, show a considerable degree of variation between patients (Office of Health Economics 1988).

2.1.2 EPIDEMIOLOGY.

Stroke is the third most common cause of death in the Western world after cancer and heart disease (Woodrow et al 1991). In 1989 there were 63,407 stroke deaths in England, approximately 12% of all deaths (Dept of Health 1991). Approximately 100,000 first-ever strokes occur in

Britain each year (2 per 1000 population per year) (Wade 1988a). The initial period following onset of stroke may be the most critical for patients, with most deaths occurring within the first 30 days (Phipps 1991). Of the patients who survive the acute phase, it is expected that 50% will be alive in 5 years (Phipps 1991).

The Royal College of Physicians, in 1974, were concerned about the rising number of patients with stroke in the community. At that time 20% of beds occupied by the elderly were due to cerebral vascular disease, most of them being strokes. After the age of 55 years the risk of having a stroke doubles with each decade (Allen et al 1988). Men have a 30 per cent higher incidence of stroke than women, but this difference is greatest before the age of 65 years (Allen et al 1988). The Office of Health Economics (1988) estimates that 50 per cent of the total number of first strokes occur in the 75 and over age group and this rate increases with age. If current demographic trends, which point to future populations containing increased numbers of elderly people continue, the implications for stroke management is that the disease will remain a significant source of morbidity (Office of Health Economics 1988). It will also place more strain on hospital and community resources (King's Fund Forum 1988).

Stroke is one of the most common causes of severe disability in adults (Woodrow et al 1991 and Dept of Health 1991). In Great Britain in 1988 there were approximately 100,000 severely handicapped patients with hemiplegia including stroke (Thompson and Coleman 1988). The death toll for stroke is considerable but a major issue for concern is the burden of morbidity and disability that stroke places on the community (Office of Health Economics 1988).

In 1988 the average health district in England and Wales spent at least three million pounds on stroke services each year (King's Fund Forum 1988). It is estimated that stroke related illness takes up just under 16,000 NHS beds every day and account for about 7.7 million lost working days each year (Dept of Health 1991). Despite these facts the King's Fund Forum believed that policy makers, members of professions and educators did not regard stroke as high priority.

2.1.3 CONSEQUENCES OF STROKE.

2.1.3.1 Motor and Sensory Dysfunction.

Frequently both sensory and motor dysfunction occur following a stroke. The maintenance of posture and normal movement requires the efficient transfer of information

between the sensory and motor systems (Hirst and Larder 1992). Disturbances in vision and proprioception, for example, will affect the quality of information received from the sensory system; this then impairs the quality of the motor systems's reactions, i.e. movement. Sensory loss seldom occurs in isolation and it compounds the loss of functional activity (Wilcock 1986).

Hemiplegia, that is, paralysis of one side of the body, is the major observable sign of stroke (Wilcock 1986 and Hirst and Larder 1992). The face, neck and trunk muscles can be involved as well as the limbs. Muscle tone alters following a stroke (Hirst and Larder 1992). Hypotonous (reduced tone) is usually present immediately after the episode and presents with limp, flaccid limbs and a reduction or absence of resistance to muscle movement (Hirst and Larder 1992). Later the muscles may become hypertonic (increased tone) where resistance to passive movement increases.

Impaired balance may cause difficulties in assuming and maintaining a vertical posture, and automatic adjustments to changes of position and antigravity movements (Wilcock 1986).

Urinary incontinence is common early on (24 per cent affected at three weeks), but gets less common (11 per

cent at six months) because of the combined effects of increased mortality and spontaneous improvement (Ebrahim 1990).

Proprioception is defined as sensory awareness of the position of body parts (Wilcock 1986). Impairment affects anti-gravity and postural mechanisms, including cortical and subcortical adjustments to tone and position.

Tactile sensation includes light touch, fine localization, two point discrimination, and discrimination of shape, size, texture, temperature, and pain (Wilcock 1986). Patients with impairment or loss of tactile sensation may demonstrate a lack of awareness of body parts.

Stereognosis is the recognition of common objects by touch (Wilcock 1986). It requires integration of various modalities such as discrimination of shape, size, weight, texture, temperature, joint position sense, fine touch and spatial conceptualization in order to interpret the identity of the object.

2.1.3.2 **Communication and Swallowing.**

Dysphasia is one of the most common language problems seen following a stroke (Thompson 1990). It can be divided into expressive and receptive dysphasia (Hirst and Larder

1992). Expressive dysphasia is the inability to express oneself through speech even though comprehension of the spoken word may be intact. Receptive dysphasia is the inability to comprehend the spoken word (Hirst and Larder 1992). Global dysphasia is a reduction of available language affecting all language modalities i.e. comprehension of the spoken and written word and expression of spoken and written language (Thompson 1990). Dysphasia (also known as aphasia) occurs in about one-quarter of conscious patients (Wade 1988b).

Dysarthria is a disorder of articulation resulting from weakness or paralysis of the muscles of articulation (Thompson 1990 and Hirst and Larder 1992). It affects articulation, resonance, voice quality, intonation and rhythm of speech although there is no language deficit (Thompson 1990 and Hirst and Larder 1992). It occurs in at least one third of conscious patients in the early stages following a stroke (Goodwill and Chamberlain 1988).

Dysphagia is a disorder of swallowing. Early investigation of dysphagia in cooperation with speech therapists is essential to detect aspiration of material to prevent avoidable bronchopneumonia (West Lambeth Health Authority Stroke Steering Group 1992). Dysphagia affects 45 per cent of acute stroke patients initially,

falling to about 1 in 10 affected by two weeks (Ebrahim 1990).

2.1.3.3 **Cognition.**

Confusion, memory loss, problems with behaviour, planning, abstract reasoning, judgement and concentration may occur after stroke (Wilcock 1986 and Thompson 1990). Cognitive impairment affects about 12 per cent of six month survivors (Ebrahim 1990). Confusion may lead to wandering, difficulty in finding the way around an environment or a lack of recognition of relatives. Coma and confusion will affect about half of all patients in the first few days (Wade 1988b).

The rehabilitation process may slow down if memory loss is present (Thompson 1990). This can cause difficulties in accurate recall of day to day activities, people and newly learned procedures (Wilcock 1986). Behavioural problems such as swearing or shouting can be frustrating for carers (Thompson 1990). Poor concentration can impede rehabilitation allowing progress to take place very slowly (Thompson 1990).

2.1.3.4 **Perception.**

A number of perceptual deficits may occur following stroke (Leiberman 1986). Failure to make sense of the external environment, perceive one's own body correctly and failure to perform a voluntary movement is a major problem in stroke patients (Leiberman 1986). When a patient presents as 'lacking in motivation', 'awkward', 'not trying' or 'he can do it when he wants but not when asked to do it', it is important to establish whether there are any perceptual problems (Mulley 1985).

Perceptual neglect is the commonest perceptual disorder early in stroke (Fullerton et al 1986). It is the tendency to ignore spatial surroundings on the side contralateral to the side of cerebral damage (Fullerton et al 1986). On reviewing the reasons why some stroke patients had failed to return home after a considerable length of stay in hospital, Adams and Hurwitz (1963) found that in about a quarter the single most important reason was the presence of neglect or a related perceptual disorder. Bernspang et al (1987) suggest that deficits in perception adversely affect self-care ability after stroke.

Thompson (1990) divides perception into four main areas:-
1) Body image and body schema which includes body image,

body schema, somatognosia, unilateral neglect, anosognosia and right/left discrimination;

2) Spatial relationships which includes figure ground, form constancy, position in space, spatial relations, topographical disorientation, depth and distance;
3) Apraxias which includes constructional apraxia, dressing apraxia, motor apraxia, ideomotor apraxia and ideational apraxia;
4) Agnosias which includes visual object agnosia, visual/spatial agnosia and tactile agnosia.

2.1.3.5 **Psychological.**

Stroke is a major stressful life event and many stroke patients require two or three years to adjust to the physical and psychological effects of their illness (West Lambeth Health Authority Stroke Steering Group 1992). Langton-Hewer (1982) believes that there is a growing awareness that stroke patients experience severe psychological and social problems that may be just as important as the mechanical ones caused by the obvious physical limitations of the hemiplegia. The nature and severity of psychosocial problems may be influenced by many factors including the extent of the neurological deficit, whether or not patients are admitted to hospital, their premorbid personality and the quality of life, marital stability, and financial security. Psychological

and social factors, because of the way in which they shape the patient's motivation, influence the course and outcome of rehabilitation (Hyman 1971).

Emotionalism, fear, anxiety, depression and denial of disability are some of the psychological problems which occur after stroke (Wilcock 1986, Evans et al 1989, Price 1990 and Thompson 1990). Most research has focused on depressive disorders and less work has been done on psychological adjustment, anxiety disorders, emotionalism (emotional liability or pathological crying) or the interpersonal consequences of stroke (Allman 1991).

Emotionalism is common after stroke (House et al 1989). There is a heightened tendency to cry (or rarely laugh) such that crying occurs more frequently, more easily, more vigorously, or in circumstances that previously would have been out of character (Allman 1991). Emotionalism is associated with symptoms of a general mood disturbance and is found especially in patients with left frontal and temporal lesions (House et al 1989).

Post stroke depressions are common, severe, longstanding and often interfere with rehabilitation (Lipsey et al 1984, Eastwood et al 1989 and Price 1990). The causes of depression after stroke are not fully known (Price 1990). Robins (1976) suggests that depression in stroke patients

is a non-specific affective response to the complex physical and psychological stresses imposed by illness. Folstein et al (1977) in looking at mood disorder as a specific complication of stroke found that more stroke patients than orthopaedic patients were depressed (45% versus 10%) even though the level of functional disability in both groups was the same. They conclude that mood disorder is a more specific complication of stroke than simply a response to the motor disability. Fedoroff et al (1991) also found that the aetiology of depression following stroke is different from that associated with myocardial infarction or spinal injury.

Mood disorder, usually depression, affects about a quarter of six month survivors (House 1987). Depression is likely to be almost twice as common among patients in the first year after stroke as among the normal elderly population (House 1987). Wade et al (1987b) found that over 50% of patients depressed at three weeks remained so at one year and Robinson et al (1984) found that the duration of depression following stroke is more than six months and that the prevalence of major depressive symptoms increase steadily for the first six months post stroke. They found that the depressions were long term mood disorders and that they had an important impact on functional recovery and rehabilitation (Robinson et al 1984). In contrast, Schubert et al (1992a) found that

hospitalised stroke patients showed a reduction in depression during the rehabilitation admission.

Depression frequently goes unrecognised or untreated (Ebrahim 1990, Robinson et al 1983 and Feibel and Springer 1982). Rabins (1992) suggests that prompt and adequate treatment of depression may reduce the long-term morbidity of stroke. House et al (1989) found that General Practitioners (GP) were aware of nearly all persistent severe psychiatric disorders in stroke patients but they displayed a passive attitude to therapeutic intervention. In another study, Wade et al (1987b) found that few depressed patients at six months were on antidepressant medication.

Robinson and Price (1982) found that depressive disorders were more common during the period from 6 months to 2 years and that there was no correlation between the degree of physical or cognitive impairment and the severity of depression. Collin et al (1987) also found a high proportion (42%) of patients, between one and two years post stroke, to be depressed. Johnson (1991) suggests that the concept of "post-stroke depression" may be too broad and nonspecific and that aetiological factors have not yet been adequately appraised.

Depression has a negative impact on function, cognition and on ability to participate in community and family activities (Bacher et al 1990 and House 1987). Towle (1988) in a study looking at participation in extended activities of daily living (such as shopping, social outings) and depressed mood after stroke, found that some patients were often capable of carrying out an activity but never actually did it. As the patients were depressed they were unwilling to do much for themselves. Similarly Schubert et al (1992b) found that depression lowered functional ability by increasing fatigue, hopelessness and decreasing motivation. Parikh et al (1990) found a sustained adverse effect of depression on functional recovery after stroke even after the depression had improved.

The potential reversibility of depression emphasises the importance of early identification of depression following stroke (Labi et al 1980 and Feibel and Springer 1982). The onus is on the rehabilitation process to intervene aggressively to alleviate post stroke depression thereby increasing a patient's opportunity to achieve a high quality of life and full community reintegration (Bacher et al 1990). In some studies selection bias has occurred as the patients with dysphasia or confusion have been excluded (House 1987). The diagnosis of depressive disorder is particularly difficult in patients with

aphasia, when features such as unexplained weight loss, sleep disturbance or irritability might be the only pointers to the diagnosis (Allman 1991). Despite these difficulties in assessment, depression appears to be common in aphasic patients following stroke (Robinson 1981).

Johnson (1991) suggests that too much emphasis is placed on depression, which results in a failure to look adequately for other psychiatric sequelae of stroke, and that patients should be examined systematically for evidence of psychiatric disorder other than depression, such as anxiety disorders and personality change. Astrom et al (1992) found that three years after a stroke, the prevalences of dizziness, anxiety/nervousness, and sadness were significantly higher than before the stroke and than in the general population.

2.1.3.6 **Social function.**

A marked social deterioration often follows a stroke (Astrom et al 1992 and Anderson 1992) and many stroke survivors do not return to normal social life even after physical disability has ceased to be a serious obstacle (Labi et al 1980, Ebrahim 1990 and Niemi et al 1988). Hemiplegics in particular, but also many unimpaired and nondisabled stroke patients, appear unable to maintain or

reorientate their interests and activities by themselves and they are inadequately supported by others (Viitanen et al 1988).

Labi et al (1980) found that stroke patients had greater difficulty in resuming activities outside the home than inside. However, survivors who lived alone were less likely to reduce outside socialization. Similarly the Framingham study (Gresham et al 1975) found that 62 per cent of stroke patients showed a decrease in social activities outside their homes.

Niemi et al (1988) showed that in spite of a good recovery in terms of discharge from hospital, activities of daily living, and return to work, the quality of life of most patients had not been restored to the prestroke level. The location of lesion, paresis, coordination disturbances, and especially subjective tendency to depression were highly correlated with a deterioration in the quality of life (Niemi et al 1988). These results suggest that much more attention should be paid to the quality of life of stroke patients. Johnson (1991) argues that the possible relevance of social supports and social functioning to post-stroke depression has not yet been adequately addressed. Patients with the greatest post-stroke physical, intellectual, or emotional impairment need the most social intervention to prevent them from

withdrawing and becoming socially isolated (Robinson et al 1985).

Granger et al (1988) found that six months after discharge, there was a trend for those persons who were more independent in activities of daily living (ADL) and mobility, as measured by the Barthel Index, to be more satisfied with life in general, to have more person to person contacts, and to be more active in the community. In a follow-up study of patients discharged from a stroke unit, Corr and Bayer (1992) found that only 4% of the patients were involved in domestic, leisure and outdoor activities. They also found that those living in institutional care appeared to have particularly poor social functioning, with little contact with everyday life outside and apparently minimal effort made to reintegrate them into the community in any way.

Belanger et al (1988) found a decrease in the practice of activities such as paid work, housework, management of personal affairs and leisure activities six months after discharge. They found that absence of serious motor and language after-effects, a high level of perceived health condition, accessible facilities, proximity of relatives and the ownership of a car were the factors most strongly associated with continued social function post stroke.

Astrom et al (1992) found that after 1 year, the pattern of leisure-time activities remained essentially unchanged. Patients who had not resumed physical activities like gardening and hiking by 3 months did not do so later. They also found that at 3 months after the stroke, the proportion of patients who had contacts with neighbours, friends and relatives other than a spouse or children was significantly reduced.

Lawerence and Christie (1979) found that three years after a stroke, survivors had ceased work prematurely, their interpersonal relationships had deteriorated, and over 70% viewed their future with uncertainty or gloom. They suggest that 40% would have been assisted by social work assessment, counselling and direction to appropriate community services. Similarly Ahlsio et al (1984) found that most of the patients had experienced a decrease in their quality of life and no improvement was observed during a period of two years.

Astrom et al (1992) found that stroke involved a very marked reduction in global life satisfaction, being lowest at 3 months after the stroke, when only 32% of the patients reported their life as being good. Compared with a general elderly population, at 3 years after stroke the patients had more psychiatric symptoms, lower functional

ability, and a pronounced reduction in life satisfaction (Astrom et al 1992).

Using the Frenchay Activities Index, Greveson and James (1992), in a follow-up study three years after stroke, found that leisure and social activities were markedly restricted despite the low level of physical disability. They also found that little or no help had been given to patients to enable them to participate in leisure interests such as gardening, painting or sewing, and patients thought that this could have appreciably improved their quality of life.

Like Lawerence and Christie (1979) and Ahlsio et al (1984), Astrom et al (1992) suggests that psychosocial intervention and support early after stroke and throughout the following years are important to prevent permanent reduction in life satisfaction for stroke patients and their families.

2.1.3.7 **Family Stress/Carer's Burden.**

Informal carers provide most of the support for patients (Ebrahim 1990). Anderson (1992) found that the majority (88%) of the supporters were drawn from the family and 70% were women. Allen et al (1988) suggest that following a

stroke, it is easy to concentrate upon patients to the exclusion of families.

Ebrahim and Nouri (1987) found that over two-thirds of relatives and friends living with stroke patients said that they had to give more help than before the stroke, and for the majority this burden of caring had had an adverse effect on their lives. Those stroke patients thought to need more help were more disabled, more cognitively impaired, had spent longer in hospital, and were more likely to suffer with speech impairment and urinary incontinence than others not receiving more help from their companions.

Brocklehurst et al (1978a) showed that spouses of patients with stroke are likely to get depressed. Carnwath and Johnson (1987) found that this depression is likely to be present for a considerable time after the stroke and that it was more common three years after the stroke than in the first year. Spouses had given up jobs and interests, had social and financial problems and felt isolated from friends and relations.

Sanford (1975) suggests that carers' problems are neglected and they are unable to cope with their dependants at home. He found that 92% of carers were able to identify problems which, if solved, would restore a

tolerable situation at home. Evans et al (1989) found a high level of anxiety among caregivers.

Greveson and James (1992) found that three years after suffering a stroke few patients or their carers were in contact with hospital services, and most care and support came from informal carers. Many patients and carers were unaware of available sources of help, or how to obtain advice. Also many people commented that they felt 'abandoned' after hospital discharge, and others would have appreciated a named person to visit, or a telephone call after discharge to offer support and provide an ongoing source of information and advice (Greveson and James 1992).

Draper et al (1992) conducted a study, the aim of which was to compare elderly co-resident caregivers of stroke and dementia sufferers to determine whether caring for those with predominantly mental disability (dementia) is more stressful to caregivers than caring for those with predominantly physical disability (stroke). They found that elderly co-resident caregivers for stroke and dementia patients experience similar degrees of burden and high levels of psychological morbidity. Psychiatric aspects to chronic disability, rather than physical aspects, were found to be more stressful to caregivers (Draper et al 1992).

2.1.4 **TREATMENT.**

No current acute treatment is successful in reducing the mortality or limiting the brain damage caused by stroke (Ebrahim 1990, Wade 1988a). The failure of most forms of medical therapy to influence significantly the final outcome can induce a sense of hopelessness in many health care professionals when faced with a patient who has suffered a stroke (Pearce 1983). This may be counter-productive as it could lead to the disaster of overlooking the many treatable aspects of stroke and its complications. Good management aims at preventing both the early and late complications of stroke, such as bronchopneumonia and pulmonary embolism following deep venous thrombosis in the leg (Wade 1988a). Treatment priorities depend on the state of evolution of the stroke deficit and the likely outcome, which can be determined quite early on (Allen et al 1988).

The aim of early treatment for acute ischaemic stroke is to reverse or limit the degree of brain dysfunction (Sandercock and Willems 1992). Although it is important to ensure that treatment aims to reduce mortality - or at least does not increase it - it is also important to ensure that treatment reduces disability in survivors (Sandercock and Willems 1992). Granger et al (1975) suggest that the objectives of stroke care should be

maintenance of a low mortality rate and rehabilitation of surviving patients to the highest functional outcome possible. The two principal courses of action that medical management takes are, to increase cerebral blood flow in order to save the area of brain tissue surrounding the site of the lesion, and secondly to mitigate the damage borne by brain cells during the ischaemic period (Office of Health Economics 1988).

After an acute stroke, as with any condition, therapy must start with general measures to facilitate natural recovery and prevent complications which may cause death or hinder recovery (Allen et al 1988). General treatment measures include attention to the nursing posture, micturition, pressure areas, fluid management and cardiopulmonary status (Allen et al 1988). Sadka (1991) suggests that acute care not only minimises neurological deficit, but avoids such problems as sphincter malfunction, muscle shortening, shoulder capsulitis, joint contracture, deep vein thrombosis and poor morale.

The overall chance of having a further stroke is about 10 per 100 patient-years, falling to about six per 100 patient-years after surviving the first month (Ebrahim 1990). The main factors known to increase the risk of a recurrent stroke are male sex, raised blood pressure (before and after the stroke), atrial fibrillation,

coexisting ischaemic heart disease, and age over 80 years (Ebrahim 1990).

Although there is currently no medical therapy which can be recommended for routine use in most patients with acute ischaemic stroke, Sandercock and Willems (1992) believe that trials in progress show promise of identifying effective treatments in the future. Strategies to combat the problem of stroke must consider a number of different approaches, such as the prevention and acute treatment of stroke, rehabilitation after stroke, and the need to provide supportive services for stroke survivors and their families (Effective Health Care Bulletin 1992). Prevention of further stroke is a therapeutic priority, especially in the majority of survivors who remain functionally independent after their strokes (Allen et al 1988).

2.1.5 **RECOVERY.**

The pattern of recovery after stroke is very variable, depending on the patients considered, the criteria used to define independence, and the time at which observations are made (Mayo et al 1991). Gresham et al (1975) suggest that once a patient survives a stroke the outlook for eventual recovery of function is good.

Rate, degree and timing of spontaneous recovery are not always predictable, even by experienced practitioners (Sadka 1991). Mayo et al (1991) found that four variables influence recovery time: age influenced the rate of recovery of walking and stair climbing; perceptual impairment influenced the rate of achieving independent sitting and stair climbing; and depression and comprehension influenced walking.

Spontaneous recovery can be impressive, but rehabilitation-induced recovery seems to be greater on average (Ernst 1990). Half to three-quarters of survivors achieve functional independence, mostly in the first three months (Allen et al 1988). Most (80+ per cent) survivors will be at home by 6 months (Wade 1988a). Allen et al (1988) suggest that patients should be grouped as following:

- those likely to recover;
- those who may recover with a degree of functional impairment;
- those who will not survive without serious disability.

They suggest that active therapeutic manoeuvres should be directed principally at the second group, whose outcome is uncertain and in whom reduction in lesion size may make the difference in functional outcome. Information concerning anticipated recovery patterns is useful in

discussing prognosis and making further plans for therapy and long term care (Duncan et al 1992).

The bulk of recovery of physical ability in self-care appears to occur over the first six months and is most rapid over the first three months (Sheikh et al 1978, Allen et al 1988, Wade 1988a, Ebrahim 1990, Kelly-Hayes 1990 and Anderson 1992). However, among the very disabled, almost half show improvements between six months and one year (Ebrahim 1990). Of survivors to 1 month, between 50 and 60% are functionally independent, rising to between 60 and 70% at 6 months (Warlow 1987). In contrast, Astrom et al (1992) found that no significant improvement in mobility and function was observed from 3 months after the stroke. Duncan et al (1992) found that all patients with mild or moderate motor deficits at baseline, 5 days and 30 days after stroke, were independent in ADL after 6 months. In contrast, only 56% of the patients with a severe deficit 30 days after stroke were independent in ADL after 6 months.

The following list states the factors associated with a good recovery:-

- acceptance of disability (Gersten 1975 and Henley et al 1985);
- a spouse in the home (Gersten 1975 and Henley et al 1985);

- previous independence (Henley et al 1985);
- high level of consciousness (Henley et al 1985);
- bladder control (Gersten 1975, Lehmann et al 1975, Feigenson et al 1977, Henley et al 1985 and Wade and Langton Hewer 1985)
- good visual motor coordination (Gersten 1975 and Henley et al 1985);
- early return to muscle tone, deep tendon reflexes, and voluntary motor activity (Gersten 1975 and Henley et al 1985);
- good strength in hand and trunk muscles (Gersten 1975 and Henley et al 1985);
- skill in feeding activities (Gersten 1975 and Henley et al 1985);
- youth (Granger et al 1975, Lehmann et al 1975, Feigenson et al 1977, Henley et al 1985, Gowland 1986 and Thompson and Coleman 1988);
- ability to perform personal activities (Henley et al 1985);
- ability to perform domestic activities (Henley et al 1985).

The following list shows the factors associated with a poor prognosis:-

- a long time lapse between stroke onset and rehabilitation efforts (Stern et al 1971, Gersten 1975, Feigenson et al 1977, Granger et al 1982 and Wagenaar et

al 1990);

- persistent muscle flaccidity or extreme spasticity (Gersten 1975, Henley et al 1985 and Wade 1988a);
- contractures (Gersten 1975);
- cognitive dysfunction (Gersten 1975 and Henley et al 1985);
- nystagmus (Gersten 1975 and Henley et al 1985);
- visual field defect (Gersten 1975, Henley et al 1985, Gowland 1986, Wade 1988a);
- aphasia (Henley et al 1985, Wade 1988a);
- severe motor involvement (Gersten 1975, Granger et al 1975 and Wade 1988a);
- severe sensory and/or perceptual dysfunction (Stern et al 1971, Gersten 1975, Feigenson et al 1977, Henley et al 1985 and Wade 1988a);
- associated illnesses (Gersten 1975, Gowland 1986 and Thompson and Coleman 1988);
- a history of prior stroke (Gersten 1975).

The goal of discharge home with optimal restoration of function in the shortest time possible can be best accomplished by providing intensive and comprehensive services early in stroke recovery (Granger and Kaplan 1982). Belanger et al (1988) found that the determining factors to returning home were motor function and autonomy, personal perception of health conditions, proximity of children and relatives, relatively low age,

regular presence of another person in the home, and proximity of friends.

Partridge et al (1987) conducted a study attempting to identify a pattern of recovery following stroke. The results suggest that recovery after stroke follows a predictable pattern of milestones of recovery. These milestones would facilitate the setting of appropriate goals and provide a way of examining the relations between disability, actual limitation of movement and handicap in daily life.

Moskowitz et al (1972) and Feigenson et al (1977) reported that from 61 to 85% regain independent ambulation. Moskowitz et al (1972) suggest that the recovery of the upper limb can take place without return of function. Gowland (1986) explains this by saying that unless the stroke survivor is capable of moving his fingers individually, with the normal timing and coordination required to manipulate objects in a functional manner, he will not perceive his hand as being functional. Gowland (1986) suggests that this is a contrast to the leg, which is considered functional once patients reambulate, regardless of the quality of the gait.

Duncan et al (1992) found a parallel between recovery of motor function and recovery of activities of daily living

and suggest that motor function is a particularly important determinant of physical function and independence in ADL.

2.1.6 LONG-TERM OUTCOME.

Ungern-Sternberg et al (1991) suggest that it is the premorbid status, the overprotection of the physically disabled and the determinative cognitive and mental functions that decide the long term fate of stroke patients. In a study following-up patients three years after their stroke, Soderback et al (1991) found that all the patients thought that they had not regained the same level of occupational performance as before their stroke. More than one-third reported altered social roles, leisure times and satisfaction in life activities. Sensori-motor, intellectual, and emotional impairments were reported by 80%. Disability in personal care was a problem for fewer than half the individuals and disability in domestic, housework and gardening activities was a problem for less than half the group (Soderback et al 1991).

The Framingham study (Gresham et al 1975) found that 84 per cent of patients were living at home, 80 per cent were independent in activities of daily living though 62 per cent showed a decrease in social activities outside their homes.

Many patients do not get the appropriate support they need despite being in touch with various health and social services (Ebrahim 1990). Home helps, community nurses and day hospital were the most common sources of support from the domiciliary services (Ebrahim 1990). Occupational therapists, physiotherapists and volunteers were rare visitors (Ebrahim 1990).

2.1.7 SUMMARY.

Stroke is an illness with a sudden onset, which occurs in 2 per 1,000 population per year. The effects of a stroke can include loss of motor function, loss of sensory function, communication and swallowing problems, difficulties in areas such as perception and cognition and psychological problems. It also affects social function and can put considerable strain on carers and family.

There is no medical treatment of proven value for acute stroke patents. Therefore the strategies to combat the problem of stroke must include the prevention and acute treatment of stroke, rehabilitation after stroke and resettlement into the community.

The next section describes the current rehabilitation of stroke patients. It includes information on the various

venues of rehabilitation and the benefits of this treatment.

2.2 REHABILITATION.

2.2.1. DEFINITION.

The World Health Organisation defines rehabilitation as: 'all measures aimed at reducing the impact of disabling and handicapping conditions, and at enabling the disabled and handicapped to achieve social integration' (World Health Organisation 1981:p9). Rehabilitation involves the restoration of patients to their fullest possible physical, mental and social capability (Langton Hewer 1990). It is the process of minimising the disruption a stroke causes in a patient's life (Allen et al 1988).

Rehabilitation identifies three levels of problem arising from any disabling condition: impairment, disability and handicap (Allen et al 1988). Impairment refers to the basic neurophysiological loss sustained by patients, for example, hemianopia or paralysis. Disability describes the immediate functional results of the initial loss, for example, paralysis may result in difficulty walking. Handicap refers to the final consequence of the disability upon patients' life, for example, hemianopia might lead to loss of driving ability or loss of job which would be a severe handicap.

The Joint Committee for Stroke Facilities in the United States suggested that rehabilitation offers the only means by which stroke persons can return to the normal stream of daily living (Peszczynski et al 1972). The committee summarized the accepted principles of rehabilitation for stroke as follows:-

- to prevent or minimize secondary complications;
- to compensate for sensory and perceptual loss;
- to substitute for lost motor function;
- to provide environmental stimulation;
- to encourage socialization;
- to produce a high degree of motivation;
- to enable independent function and home living;
- to achieve vocational rehabilitation when feasible.

One expression of achievement of rehabilitation goals is to discharge patients home rather than to long-term care facilities (Granger et al 1975) and Ungern-Sternberg et al (1991) suggest that the primary goal of rehabilitation after stroke is a complete recovery of neurological deficits to facilitate social and occupational reintegration.

2.2.2. PROVISION OF REHABILITATION.

Many studies have attempted to assess the role of rehabilitation in reducing the disability caused by a stroke. At present a lot of questions are still unanswered; for example, how should rehabilitation programmes be carried out? when should rehabilitation begin? and where should it be carried out?

Certain facilities are needed in order to provide a rehabilitation service. A Kings Fund Report (1988) on stroke suggests that each health authority should have a district stroke policy which lays down standards, identifies services, and allocates resources. An ideal stroke service should ensure a smooth transition from acute nursing care through active rehabilitation on to long term support if necessary (Wade 1990).

The exact mechanism by which recovery occurs following a stroke is not fully understood. Prior to commencing a rehabilitation programme, Langton Hewer (1990) suggests that it is necessary to ascertain the precise nature and severity of any neurological, or other deficits that exist, for example, level of consciousness, arm function and mobility. This assessment provides a logical basis for treatment and management.

Effective rehabilitation should encompass the physical, psychological and social management of the disabilities which result from stroke (Dept of Health 1991). Comprehensive rehabilitation requires the use of a team approach to optimize the functional recovery of the stroke patient (Czyrny et al 1990 and Falconer et al 1993). Participants in the rehabilitation process include nurses, occupational therapists, physiotherapists, speech therapists, dietitians, chiropodists, social workers, psychologists and doctors. They need to work as a team where there is trust and respect for each other's skills. Members of this team remain expert in, and responsible for, their disciplines yet engage in interaction to devise a coordinated treatment plan.

Rehabilitation includes many processes - assessment, provision of information and advice, teaching new techniques, counselling, giving of aids and equipment, teaching relatives, and adapting the environment (Wade 1990). These are difficult to separate and patients vary greatly with unpredictible outcomes which are difficult to measure (Wade 1990).

Evaluation of the effects of rehabilitation has to take into account the spontaneous recovery that occurs after a stroke, the heterogeneity of the impairments caused by strokes, the number of patients needed to make adequate

measurements of treatment effects, and the effects of selecting patients for therapy (Ebrahim 1990).

Rehabilitation is thought to require patients' full participation and is therefore at least partially controlled by patients' efforts (Partridge and Johnson 1989). Henley et al (1985) found that patients' attitudes towards and ability to co-operate with treatment is as important as the actual amount of treatment provided.

Partridge and Johnson (1989) carried out a study with patients who had suffered a stroke or fractured a wrist, to look at whether patients' perception of control over their disability and treatment would affect their outcome. They found that those with more perception of control were more adaptive in stressful situations and thus measuring patients' perceptions may be a predictor to better health outcomes in patients with physical disabilities. Their results suggest that it may be useful to foster patients' belief in their own control which is in contrast to most hospital care, that is, the professional person is manifestly in control and there "to get you better."

Licht (1975) suggests that in the field of disease-disability, motivation includes the idea of arousing in patients the desire or willingness to initiate or sustain efforts to overcome their handicap not simply because they

are advised or ordered to work but because they identify and accept the reason for the goal. The goal is independence; the method is physical activity with its accompanying fatigue, boredom, stress, frustration and indignity, but also the triumphs of improvements, even though small. Motivation may come from within or from outside patients (Licht 1975) and patients who have no motivation present a big problem in rehabilitation (Andrews and Stewart 1979). Chiou and Burrnett (1985) suggest that if some additional time were spent with the patients at the onset of their rehabilitation programme to determine their goals as influenced by their values, their rehabilitation time might be shortened.

Dzau and Boehme (1978) developed a family team programme which consisted of role descriptions presented by the representatives from the various disciplines involved in the rehabilitation process and a discussion of individual family-patient problems. They found that the programme was a practical instrument for expanding stroke rehabilitation and for including the needs of the patients and their families, and participation of the families.

2.2.3. SELECTION OF PATIENTS.

There are no set clinical criteria for selecting those stroke patients who are most likely to benefit from

comprehensive rehabilitation. The Edinburgh Stroke Study (Garraway et al 1981a) began to select subgroups of patients who were conscious and had an established or developing hemiplegia (approximately 25% of all patients with stroke). Patients with a poor prognosis for life and independence, and patients who were likely to recover with little or no therapy, were excluded. The investigators attempted to refine selection further and administered a clinical examination to the patients at various intervals and classified them into three categories (good, intermediate, or poor) on the basis of prognosis for successful rehabilitation.

Dombovy et al (1986) suggest that criteria for selection of patients for rehabilitation should reflect the following points:

- decreased alertness, inattention, poor memory, and an inability to learn new tasks or to follow simple commands imply that a patient is not ready or appropriate for intensive rehabilitation;
- because of their inability to recognise their deficits and their carelessness toward the neglected side, patients with severe denial or neglect of the affected side are often difficult to motivate in therapy;
- significant associated medical problems, particularly cardiovascular disease and degenerative joint disease, may limit a patient's participation in therapy;

- language difficulties (aphasia) and the degree of weakness may have less of an impact on independence and the return home;
- the presence of a caring and able spouse may be one of the most significant positive factors in the outcome of rehabilitation;
- other social and economic factors play important but difficult to define roles;
- education of family members may be as important as rehabilitation of the patient.

Wade (1988a) acknowledges that it is difficult to identify the patients who will, or might, benefit from rehabilitation. He suggests the mildly disabled may benefit because they may be made perfect, the moderately disabled as they stand to gain so much if they can be restored to active life, the severely disabled because they need it the most or perhaps no one as the benefits of rehabilitation are not proven.

If rehabilitation is only offered when a return to work or a high score in self-care and mobility can be guaranteed in a short time, then some patients may be denied the chance of living in a home environment (Penington 1992). Instead they may be forced to accept nursing home care with all its restrictions, including separation from their family (Penington 1992).

2.2.4. BENEFITS OF REHABILITATION.

An obstacle to evaluating the benefits of stroke rehabilitation is the variability in rehabilitation practice: criteria for patient selection vary among institutions, and the interval between the onset of stroke and the commencement of rehabilitation varies as does the type and duration of therapy (Dombovy et al 1986 and Ebrahim 1990). Another difficulty is that the measure of outcome is not uniform among institutions, for example, multiple indices of functional capacity and activities of daily living are used (Dombovy et al 1986). Direct comparison of the results of treatment between different rehabilitation units is not possible (Office of Health Economics 1988). Even if the pattern of remedial treatment is very similar between centres, patient characteristics are going to vary, thus influencing the outcome of therapy.

Evaluation of the effects of rehabilitation has to take into account the spontaneous recovery that occurs after a stroke, the heterogeneity of the impairments caused by strokes, the number of patients needed to make adequate measurements of treatment effects, and the effects of selecting patients for therapy (Ebrahim 1990). The nature of therapy itself must be better defined so that the effects of standardized types and amounts of treatment can

be compared (Ebrahim 1990). Garraway (1982) in his study of a stroke unit was able to establish the coverage of physiotherapy and occupational therapy and the length of time before commencing treatment but was unable to establish information about what methods of rehabilitation were used.

Sivenius et al (1985) suggest that the impact of rehabilitation on activities of daily living appears smaller than on motor function. Ernst (1990) believes that the type of treatment does not matter as long as the stroke patient gets some sort of treatment and suggests that rehabilitation should begin as soon as possible after the acute event. Also Ottenbacher and Jannell (1993) suggest that functional improvement following a stroke appears to relate to early treatment but not to the duration of treatment.

There has only been one large study carried out in Britain looking at the benefits of rehabilitation. The Northwick Park study shows that some rehabilitation is undoubtedly better than none, very intensive rehabilitation is probably more effective than conventional treatment and improvement seems to occur within 3 months, though it is sustained for 1 year (Smith et al 1981).

Dobkin (1989) questions whether improvements following an acute stroke are the consequence of a rehabilitation programme. He suggests that though therapy seems to be of benefit, how improvement comes about is not clear.

2.2.5. VENUE FOR REHABILITATION.

2.2.5.1. Stroke Unit.

The definition of a stroke unit ranges from a specialised multi-disciplinary team who provide services wherever a patient is situated to a defined ward of variable size on which care is provided by a stroke team (Effective Health Care Bulletin 1992), although it is often used to imply both (Gladman 1992). Common features of stroke 'units' include a multi-disciplinary approach and a well organised mode of delivery of services (Effective Health Care Bulletin 1992). A stroke unit gives the opportunity to concentrate expertise in one place, to evaluate the different components of the rehabilitation service and to undertake clinical research (Langton Hewer 1982). Collaboration within the team and coordination of resources are designed to raise the standard of care, ensure adequate and appropriate therapy, reduce complications and encourage social, psychological and functional adjustment (Stevens 1989).

One of the main recommendations of the Royal College of Physicians Working Group on Stroke (1974) was that there should be a few experimental stroke units that might have the following objectives:-

- to act as a focal point for the development of facilities for disabled stroke patients;
- to act as an educational centre for doctors, social workers, and therapists;
- to initiate research.

In describing how the Edinburgh Stroke Unit was established, Akhtar et al (1982) found that the creation of the unit did not involve the recruitment of extra staff, and any difference in performance was due to its organisation rather than to increased staffing. Stevens and Ambler (1982) considered that it may be more effective and efficient to coordinate a multidisciplinary team to treat patients in a single department with appropriate facilities.

In 1984, Stevens and Isaacs compiled a report on information collected about the operations of the stroke units that had been established in the United Kingdom. By that time all the stroke units had a major emphasis on rehabilitation and this rehabilitation was based on multidisciplinary assessment and unified management by a

team of nurses, doctors, occupational therapists, physiotherapists, speech therapists and social workers.

The evidence of the benefits of stroke units to date does not prove the efficacy of them but it gives encouraging support - especially to taking patients to units soon after stroke onset and beginning therapy early (particularly occupational therapy), encouraging the participation of family members, and having an integrated multidisciplinary team (Anderson 1992 and Gladman 1992). Anderson (1992) found in the stroke units in Greenwich that four-fifths received some physiotherapy in the first month, and two-fifths had occupational therapy. Physiotherapy tended to be given most to patients with moderate or severe disability; occupational therapy was given when patients were less disabled and was much less likely to go to patients who were incontinent (Anderson 1992).

2.2.5.2 **Stroke Unit Versus Medical Unit.**

Barer (1990) suggests that a period in hospital, at least long enough for the patient's medical condition to stabilise and for the family to understand the principles of rehabilitation and the potential for recovery, seems to have advantages. Since the establishment of stroke units, there have been studies carried out to compare the outcome

of patients following treatment in both the stroke units and on general medical or geriatric units. Garraway et al (1980a) carried out one such study and completed a randomized control trial comparing the management of elderly patients with acute stroke in a stroke unit and medical unit. A higher percentage of the stroke unit group were independent on discharge than the medical unit group. This study showed that the stroke unit improved the natural history of stroke by increasing the proportion of patients who returned to functional independence (Garraway et al 1980a).

In a follow up of the trial Garraway et al (1980b) showed that the improvement in functional outcome achieved by the time of discharge from stroke unit had disappeared by one year. They suggest that factors such as the overprotection by the families of patients who have been treated in stroke units may have influenced these findings (Garraway et al 1980b).

In a similar follow-up trial Strand et al (1985) found that the gains achieved by the stroke unit were still present a year later. Davidoff et al (1991) demonstrated that inpatient rehabilitation appears to be effective and that most patients maintain gains achieved during inpatient rehabilitation through one year follow-up.

Other studies have also found that a higher percentage of stroke unit patients were independent at discharge and recommend that patients with a stroke are rehabilitated in stroke units (McCann and Culbertson 1976, Feigenson et al 1977, Feigenson et al 1979, Blower 1982, Indredavik et al 1991 and Anderson 1992).

Stone (1987), in a feasibility study, showed that it was possible to apply the principles of stroke unit management to patients and their families on general wards with the creation of a multi-disciplinary stroke therapy team and the evolution of a family support service. The advantages of the service were speedy referral to therapists, development of a team approach, provision of better information and psychological support to patients and families, and more speech therapy and occupational therapy than was provided on the general medical wards.

Despite these findings Garraway and Prescott (1977) and Wade (1990) believe we should still question the benefits of stroke units. On studies to evaluate the effectiveness of a stroke unit, Garraway and Prescott (1977) suggest that if the study shows that a particular stroke unit is able to return a higher proportion of patients to the community than general medical units, it is not possible to assume this will happen wherever stroke units are set up. Apart from any general benefits that units of this

type may have, the results in Garraway's (1980b) study may have been influenced by the particular staff employed at the unit, the staffing levels or methods of providing rehabilitation. This can only point the way to the need for further evaluation at other centres, and if similar findings are made elsewhere, wider inferences may be justified. Similarly Wade (1990) believes that it is more likely that it is the quality of care given by the staff involved in the service rather than the 'physical' facilities that matter, be they medical, or stroke units. He concludes that still more research is needed to decide whether stroke units, which are expensive facilities, can alter any aspect of outcome, and whether the benefit is worth while.

Many of the advantages of special units, such as staff enthusiasm, stimulus to research, development of special experience and skills, are often difficult to measure (Allen et al 1988 and Anderson 1992). Therefore, they are often not considered when cost effectiveness equations are drawn up to compare general medical and specialised stroke units.

Although Garraway (1982) did not find that admission to the stroke unit resulted in an intensive use of therapy he did find almost universal coverage of physiotherapy and occupational therapy and shorter delays before commencing

treatment. Keith and Cowell (1987) in a study comparing time in treatment between stroke units and stroke patients on rehabilitation wards found that time in treatment was greater on the stroke unit. He suggests that this may have happened because treatment took place in the stroke unit rather than having patients travel from one department to another. Anderson (1992) also found that stroke unit patients were more likely to receive occupational therapy than those on medical wards.

The timing of rehabilitation may also be important. Early access to a rehabilitation team may be more important than the actual amount of therapy given (Ebrahim 1990). In the Edinburgh stroke unit trial Garraway et al (1981) showed that although stroke unit patients received fewer hours of therapy contact, they achieved independence sooner than the medical ward patients. Stroke unit patients were seen by an occupational therapist within one week, whereas medical ward patients were seen by three weeks on average. By contrast, physiotherapy was received within the first week by both stroke unit and medical ward patients. This may mean that early access to the team is important, but it may also be that it is the occupational therapy intervention that is crucial (Garraway et al 1981).

Though there is still some question as to where the best venue for treatment is, inpatient rehabilitation does lead

to increased levels of function (Granger et al 1979 and Granger and Hamilton 1990).

2.2.5.3. **Home Care.**

Providing rehabilitation at home is increasingly being considered. As the reasons for admission were principally the need for nursing care in association with social problems at home, increased domiciliary support and early day-hospital care might well diminish further the number of stroke patients admitted to hospital (Brocklehurst et al 1978a and Warlow 1987).

Many stroke patients can be adequately managed at home but there are certain circumstances when hospital admission should be seriously considered (Jones and Hall 1983, Mulley 1985, Warlow 1987 and Wade 1988a):-

- if patients are unconscious;
- if patients live alone or if main carers are frail;
- if patients are restless, cannot swallow or are so densely paralysed that regular turning would be impossible;
- if there is a possibility of a treatable condition such as subdural haematoma, tumour or meningitis;
- if patients fail to improve after an initial period of observation;
- if patients or relatives wish the patient to go to

hospital;

- if nursing support is not available.

In a study comparing home care and inpatient rehabilitation, Bryant et al (1974) found that home care patients had shorter hospital stays, had fewer readmissions for recurring strokes, received continuity of care for as long as was needed, were a cheaper service, had fewer deaths, and were more able to be discharged and remain self-sufficient in the community. The criteria, in Bryant's study, for home care were that the physican requested home care, that a plan of care was made, that patients were medically fit for transfer from hospital to home, and that patients required one or more of skilled nursing care, physiotherapy, social services, occupational therapy or speech therapy.

Several other studies have been carried out and Wade et al (1985b) in a trial comparing home-care services with hospital care noted equal recovery. There did not appear to be greater stress on families, despite severe initial disability in 27% of the patients managed at home. He concluded that outpatient rehabilitation and home-care are feasible alternatives to hospital rehabilitation. They also found that many professionals agreed on the need for the home care service, but few were committed to using it

(Wade et al 1985b). Such resistance may be an important factor in determining the success of new services.

In a more recent study Young and Forster (1991) compared home physiotherapy with day hospital. At 8 weeks they found that both groups showed further improvement in physical abilities. The home treatment group showed a greater improvement in the ability to use stairs and walk outdoors. As the two groups differed in type of input and amount, it is difficult to discern which is the more effective. Also at six months after discharge both groups showed a significant improvement in functional ability (Young and Forster 1992). There were indications that home physiotherapy was more effective than day hospital care although the difference between the two groups was modest.

Bamford et al (1986) suggest that a stroke service that provides a facility for rapid outpatient and domiciliary diagnosis as well as a rapidly acting domiciliary nursing team might reduce the number of patients with stroke admitted to hospital without adversely affecting the quality of patient care. Bjorneby and Reinvang (1985) also recommend that more treatment should be given in the home. They found that patients seem to have difficulty in transferring the skills learned in hospital to the home situation and in maintaining them. Andrews and Stewart

(1979) suggest that a home orientated rehabilitation programme has the advantage of training a patient in the environment in which he has to live and also allows the relatives to see what he patient can do.

2.2.5.4 **Outpatients.**

Stroke outpatients may receive rehabilitation in hospital physiotherapy or occupational therapy outpatient departments, in day hospital, or at home when domiciliary services exist (Gladman et al 1991). Gladman et al (1991) in a study carried out in Nottingham found that patients in day hospital received therapy for 22% of each attendance. Patients attending outpatient departments who received both occupational therapy and physiotherapy spent 51% of their time in therapy. Gladman et al (1991) suggest that outpatient departments are more efficient in their delivery of rehabilitation than day hospitals and would be more appropriate for patients requiring only occupational therapy or physiotherapy or both.

Outpatient rehabilitation improves performance in activities of daily living among younger patients suffering less severe strokes (Ebrahim 1990).

2.2.5.5 **Day Hospital.**

Stroke is the commonest condition amongst Day Hospital attenders (Gladman et al 1991 and Hildick-Smith 1980). Day hospitals claim to be active and therapeutic (Hildick-Smith 1980), and the diagnoses and disabilities of patients and the types of staff available seem to support this. Hildick-Smith (1980) found that only 2% of patients attended for social reasons.

The Northwick Park Study (Smith et al 1981) is the only one that addresses the benefits of day hospital exclusively. Smith et al (1981) found that the degree of improvement correlated strongly with the amount of intensive therapy received in day hospital. They found that only 11% of stroke patients were suitable for this intensive therapy but believed that the treatment was effective and realistic for this selected group.

Day hospitals do have several advantages over outpatient departments. It is relatively easy for multidisciplinary input to be organised in day hospital. Time spent in social activities may, for lonely elderly stroke patients, be vital for the maintenance of morale (Gladman et al 1991).

2.2.6. FOLLOW UP INTERVENTION.

Tangeman et al (1990) carried out a study looking at intensive rehabilitation approximately one year post stroke. The rehabilitation consisted of two hours of individual occupational therapy and physiotherapy four days a week and one day of group activities for four weeks. Only those living in the community and mobilizing unaided were accepted into the study. At the end they demonstrated a significant improvement in weight shift, balance, and activities of daily living. As the patients were recruited via the local media the authors felt the subjects were a motivated group.

Wade et al (1992) carried out a study to look at the effects on mobility of physiotherapy given to patients who would not be expected to show much spontaneous change and who had their stroke more than one year previously. They found that intervention of an experienced physiotherapist late after stroke specially improves mobility, albeit by a small amount, but the effects did not seem to be maintained.

2.2.7 SUMMARY.

Rehabilitation aims to restore stroke patients to as independent a life as possible. It uses a

multidisciplinary team to optimise the functional recovery of stroke patients. The team may be based in a specialised stroke unit or on a medical ward. Other venues for rehabilitation include outpatients, day hospital or in the patients own home.

Rehabilitation is believed to improve the patient's prognosis of functional recovery. However, exactly how this improvement comes about is unclear and the subject of much current research.

The next section describes occupational therapy, which is one member of the multidisciplinary team involved in the rehabilitation of stroke patients.

2.3. OCCUPATIONAL THERAPY.

2.3.1 DEFINITION OF OCCUPATIONAL THERAPY.

Occupational Therapy is defined as "the treatment of people with physical and psychiatric illness or disability through specific selected occupation for the purpose of enabling individuals to reach their maximum level of function and independence in all aspects of life" (College of Occupational Therapy 1990:p1). The Occupational Therapist assesses the physical, psychological and social functions of the individual, identifies areas of dysfunction and involves the individual in a structured programme of activity to overcome disability. The activities selected will relate to the consumer's personal, social, cultural and economic needs and will reflect the environmental factors which govern his/her lifestyle (College of Occupational Therapy 1990). The purpose is to prevent disability and to fulfil the person's needs by achieving optimum function and independence in work, social and domestic environments (Wilcock 1986).

Blom-Cooper (1989) found the College of Occupational Therapy definition too broad and unfocused to be useful as a description of the role so he offers the following

general description:

"Occupational therapy is the exercise of skill, care and judgement in assessing the degree of a person's mental disorder or physical disability, treating such a person accordingly, by selecting and utilising appropriate activities of that person's normal pattern of life. Such activities may be modified or applied to the defined problem of either the individual with the specific disorder or disability, or the group to which that individual belongs. The activities, modified or unmodified, are designed to achieve progress towards the attainment of maximum independence for the individual in the appropriate environment." (Blom-Cooper 1989:p15)

The American Occupational Therapy Association define occupational therapy as "the art and science of directing man's participation in selected tasks to restore, reinforce and enhance performance, facilitate learning of those skills and functions essential for adaption and productivity, diminish or correct pathology, and to promote and maintain health" (Pedretti and Pasquinelli 1990:p5).

2.3.2. HISTORY.

Occupational therapy's roots come from the philosophy of moral treatment in the early nineteenth century (Pedretti and Pasquinelli 1990). This philosophy was based on the idea that mentally ill individuals need to be engaged in creative and recreational activity with their fellow citizens.

By the end of the nineteenth century occupational therapy was practised, although in rather different forms, in most European countries and in the USA (MacDonald 1964). Occupational therapy formally began in 1917 as a result of the rebirth of moral treatment in psychiatry and of the number of chronically disabled soldiers returning from World War 1 (Pedretti and Pasquinelli 1990). At that time the role of the occupational therapist was one of using crafts to reactivate the minds and motivation of the mentally ill and the limbs of the veterans, starting them on the way to vocational training.

The title 'occupational therapy' was thought to be truly descriptive of the therapeutic aims of the service. It was believed that the person providing this service should combine many of the qualities of both nurse and instructor, should have a vital interest in people,

organising ability, and a knowledge of activities and their possibilities (MacDonald 1964).

In the 1920's (Reed and Sanderson 1983) the basic concepts of occupational therapy were:

- occupation (activities) can be mental and/or physical in nature;
- occupational therapy should be ordered or written (prescribed), especially if it is part of a medical management plan;
- one purpose of occupational therapy is to contribute to or hasten recovery from injury or disease;
- occupational therapy assists in the development and recovery of occupational (task) skills;
- occupational therapy involves the total person;
- occupational therapy has a scientific rationale;
- occupational therapy tasks and activities can be analysed and selected according to known criteria.

The following concepts did not belong to occupational therapy:

- occupational therapy should not be used as a means of keeping a person busy with no other objective in mind;
- occupational therapy does not teach specific job skills or provide selected vocational training for industrial workers;
- occupational therapy does not provide an employment

service for unemployed workers;

- occupational therapy should not be an unplanned, haphazard programme of activities.

The first school of occupational therapy in Great Britain was started at Bristol in 1930 (MacDonald 1964). With the implementation of the National Health Service Act in 1948, came a greater awareness of the components of that service including occupational therapy.

There was a growing awareness that the job of restoring individuals to health and maximising their functional capacity was not completed by the physician, the surgeon or even the nurse exercising their various skills (Blom-Cooper 1989). Medicine was concerned with preserving life; occupational therapy was and still is concerned with the quality of life preserved, increasing the latitude of choices and the freedom of the individual who is disabled (Yerxa et al 1989). Many hospitalised patients were pessimistic about the future pattern of their lives and often lacked motivation to leave hospital (Blom-Cooper 1989). They needed practical advice and assistance to regain the skills they required to function adequately in paid employment or domestic tasks, and thus to establish as much personal autonomy and independence as possible. Activities of daily living (ADL) were expanded to meet the needs of patients returning to the community.

Rehabilitation units were developed with programmes to retrain skills for independent living (Wilcock 1986). Gradually functional ADL retraining became a major component of occupational therapy intervention in stroke rehabilitation (Wilcock 1986). The goal in occupational therapy is to enable patients to engage in daily activity (Eakin 1991a).

There have been four common propositions that have characterized the profession throughout its history:

- the use of occupation or purposeful activity can influence the state of health of an individual;
- individuals and their adaptation and total functioning must be viewed with respect to their own environment, and remediation must take into consideration all the physical, psychological and social factors;
- inter personal relationships are an important factor in the occupational therapy process;
- occupational therapy is an adjunct to, and has its roots in medicine and must work in cooperation with medical professionals and other persons involved as health-care providers to ensure maximum benefits for clients (Hopkins and Tiffany 1988).

The core skills of occupational therapists according to Joice and Coia (1989) are:

- the use of selected activity, which has purpose and

meaning to the individual as a treatment medium;

- activity analysis, which is the ability to break activities down into physical, cognitive, interpersonal, social, behavioural and emotional demands made on patients and an understanding of how they may be used effectively to meet the needs of the individual;
- assessment and treatment of functional capabilities, which is the ability to assess and determine the extent to which a disturbance of mental state is affecting the functional capabilities of an individual, and the appropriate treatment for any problems identified.

2.3.3 THEORY/MODELS OF PRACTICE.

The philosophical base of occupational therapy is that man is an active being whose development is influenced by the use of purposeful activity. Human beings are able to influence their physical and mental health and their social and physical environment through purposeful activity (Hopkins 1988).

Mosey (1981) maintains that a conceptual model describes the way a profession perceives itself, its relation to other professions and to society. The model of a profession is characterised by a description of the profession's philosophical assumptions, ethical code, theoretical foundation, domain of concern, tools, and the

nature of and principles for sequencing the various aspects of practice (Mosey 1981). Models should indicate the boundaries of the profession and distinguish it from other health care disciplines (Krefting 1985). They guide treatment by outlining what to do, how to do it, and why to do it. They also act as a unifying basis for the profession.

Models of practice have been developed for occupational therapy as a theoretical definition of the profession which is more concrete than the philosophy. Reed and Sanderson (1983) suggest that there is no ideal model of health for occupational therapy to follow. They also suggest that occupational therapists must select the best aspects from the health models which most closely fit the beliefs and values of occupational therapy and that therapists may need to develop their own definition of health in which the performance of occupations is viewed as the central measure of health status.

In the mid-1960's occupational therapy as a profession began to look at itself and the medical model (Mosey 1981). Subsequently a number of models for occupational therapy were proposed. Models can evolve as a result of changes in practice or via research into the profession's effectiveness. Tyrer and Steinberg (1987) suggest that a good model is a vehicle to progress and although

sentimental attachment may develop to one, it will need to be replaced when it starts breaking down. The four models of practice in occupational therapy described below have evolved out of a concern for articulating a model unique to occupational therapy.

2.3.3.1 **Model of Purposeful Activity.**

Fidler and Fidler (1963) based their model on the belief that purposeful activity provides the incentive and opportunity for individuals to achieve mastery and thereby add to their sense of competence. The model is based on the frameworks drawn from social and individual psychology that discuss human action and the role of activity in development, adaptation and the human existence (Reed 1984).

Fidler and Fidler assume that purposeful activity enables the individual to learn those performance skills which are necessary to create a balance of skill clusters which in turn will maintain the self, satisfy individual needs and contribute to the society at large (Reed 1984). They believe that every activity has social, cultural, and personal meaning and that activities can provide the basis for exploration and learning, practising, and achieving mastery (Hopkins and Tiffany 1988). They permit participation from the simplest, developmentally earliest,

and nonverbal levels. Central to the model of purposeful activity is the role of performance and skill development in the process of human adaptation (Reed 1984).

They suggest that it is the task of the occupational therapist to understand the meaning of activity and to know how to determine the potential of each given activity for promoting performance (Hopkins and Tiffany 1988). Implementation of occupational therapy using this model involves matching the activities to individual deficits, learning readiness, intact facts and values (Reed 1984).

2.3.3.2 **Model of Adaptation.**

The basic assumption of Mosey's model of adaptation is that an individual is able to interact effectively and with satisfaction to the self and others through learning those adaptive skills which are characteristic of a mature well adjusted individual (Reed 1984). Mosey (1981) lists the skills needed for adaption as perceptual-motor skills, cognitive skills, drive-object skills, one to one interaction, group interaction, self identity and sexual identity.

According to this model a person is considered to be in a state of dysfunction when, in one or more adaptive skills, the individual has not attained a level, relatively

typical for chronological age and/or the individual has not attained the level needed for effective and satisfying interaction in the environment (Reed 1984).

The purpose of occupational therapy using this model is to assist the individual in progressing sequentially through the stages of development which were not attempted or never completely mastered (Reed 1984). Each individual is assessed in the seven adaptive skills to determine the level of performance attained. Information is sought relative to the environment in which the person lives or expects to return. Intervention is directed toward the learning of those subskills needed to fulfil the social roles in the expected environment (Mosey 1981 and Reed 1984).

The advantage of Mosey's model is that it recognizes that progress cannot be achieved if the individual has not reached the required developmental level (Hagedorn 1992). However, the strongly psychosocial emphasis leads to restricted applicability in physical settings (Hagedorn 1992).

2.3.3.3 **Model of Adaptation through Occupation.**

Reed and Sanderson (1983) assume that all individuals use a problem solving process; that there is a close

relationship between human beings, occupations (activities) and the environment; that a person adapts through the use of various occupations; that in adapting a person may adapt to the environment or adapt the environment; and that there must be a balance of types of occupations in an individual's life.

They define occupation as that which engages a person's time, energy and attention. They divide occupation into the categories of self maintenance (self-care), productivity and leisure and maintain that it is important for individuals to have a balance of these.

Reed and Sanderson (1983) sub-divide the environment into three categories:

- the physical environment which includes all non human aspects of the environment such as objects, housing and weather;
- the organic environment (biopsychological) which includes all human aspects of the environment such as the person's internal physical and psychological well-being;
- the socio-cultural environment which includes interactional aspects of the environment such as relationships with other human beings, organisations, roles, rules of society and cultural influences.

The purpose of occupational therapy using this model is to minimize the problems caused by changes in an individual's circumstances which disrupt that individual's ability to carry out activities. Reed and Sanderson (1983) believe that damage to the individual (illness, disability), a disruptive environment and an imbalance of types of occupations (activities) create an inability to cope and cause further deterioration in health. Adaptation through occupation means the organisation and management of occupational activities and tasks in a manner that meets the goal of achieving maximum functional independence (Reed 1984). Reed and Sanderson's model of adaption through occupation is a flexible, practical, holistic, client centred, problem solving approach (Hagedorn 1992).

2.3.3.4 **Model of Human Occupation.**

The structure and content of the human occupation model are based on the open systems and developmental models (Reed 1984). Interaction of an open system with the environment is achieved through the process of input, output, throughput and feedback. The human occupation model proposes three subsystems each of which serve a different purpose (Reed 1984). First is the volition subsystem which guides the choices of action through personal causation, valued goals and interest. Second is the habituation subsystem which is composed of habits and

internalized roles. Habits and roles function to maintain action. Third is the performance system which functions to produce action through skills such as social, cognitive and physical (Reed 1984). Change in the system is the result of the interaction of the three subsystems to produce motives. These motives are first exploration then competency and finally achievement. Exploration produces skills, competency produces habits and achievement produces roles. In each stage of life, childhood, adolescence, adulthood and ageing, the process of change which occurs through the subsystems is repeated in order to organize behaviour and to meet environmental demands (Reed 1984).

Occupational therapy can be useful in the transition from one stage to another to help the person acquire new interests, valued goals and habits (Reed 1984). It may also help the person reorganise the system to facilitate adaption to the environment and restore a normal course of occupational development. Occupational therapy's concern is with the occupational nature and behaviour of human beings. Kielhofner (1985) suggests that the field is concerned with the adaptation of persons in terms of their occupational function and dysfunction.

Occupational therapists are faced with a choice, they may adapt the method of carrying out an activity either to

promote intrinsic recovery (activity as a treatment medium) or to enable the person to perform an activity independently (activity as a goal) (Kielhofner 1985). Kielhofner (1985) suggests that in practice, occupational therapists probably use a combination of the two approaches. The skill of occupational therapists lies in obtaining the appropriate balance between the two because the promotion of adaptive recovery may be regarded as inhibitory to the achievement of intrinsic recovery.

The model of human occupation provides a structure for assessment and intervention that can be applied to the provision of occupational therapy for stroke patients (Burton 1989). This model serves therapists as a check list of the influences which operate on the individual engaged in occupational behaviour (Burton 1989). It enables occupational therapists to assess the adaption needs of the stroke patient (Pelland 1986) and it may pinpoint more precisely the source of functional deficits (Burton 1989). It also enables therapists to plan effective intervention strategies (Pelland 1986).

2.3.4 OCCUPATIONAL THERAPY FOR STROKE PATIENTS.

2.3.4.1 Aims of Occupational Therapy.

The main goals of occupational therapy programmes are to:

- evaluate human behaviour and function in terms of occupational performance, the components of that performance and the required adaptive behaviour;
- support the optimum health of each person based on the individual's needs and the community demands for occupational performance;
- develop, improve, reestablish, promote or maintain normal occupational functions and performance throughout the human life-span;
- prevent, remedy or minimize dysfunctional occupational performance and adaptive behaviour throughout the human life-span (Reed and Sanderson 1983).

Occupational therapy should lead to the overall goal of assisting patients to become more independent, enabling them to return to as near previous lifestyle as is possible (Thompson and Morgan 1990). The following lists the aims of occupational therapy for patients following a stroke:

- to assess patients' difficulties (Peszczynski et al 1972, Sahs 1979, Turner 1981, Mulley 1985, Warlow 1987 and Curry and March 1988);

- to facilitate maximum independence in activities of daily living (Peszczynski et al 1972, Sahs 1979, Turner 1981, Mulley 1985, Pelland 1986, Strub and Levine 1987, Warlow 1987, Curry and March 1988, Thompson and Morgan 1990, Pedretti 1990a, Eakin 1991b and Gutting 1992);
- to prevent deformity (Turner 1981, Pelland 1986, Curry and March 1988, Pedretti 1990 and Gutting 1992);
- to encourage maximum return of function (Sahs 1979, Turner 1981, Pelland 1986, Warlow 1987, Curry and March 1988, Thompson and Morgan 1990, Pedretti 1990a and Gutting 1992);
- to help patients adjust to their disability (Turner 1981, Pelland 1986, Curry and March 1988, Pedretti 1990a and Eakin 1991b);
- to alleviate communication problems (Thompson and Morgan 1990 and Pedretti 1990a);
- to correct or compensate for perceptual problems (Warlow 1987, Thompson and Morgan 1990 and Pedretti 1990a);
- to liaise with other members of the multidisciplinary team (Peszczynski et al 1972, Sahs 1979, Turner 1981, Mulley 1985, Curry and March 1988 and Eakin 1991b);
- to provide necessary aids and adaptions (Peszczynski et al 1972, Sahs 1979, Warlow 1987 and Curry and March 1988);

- to resettle into the community (Turner 1981, Mulley 1985, Curry and March 1988, Pedretti 1990a and Eakin 1991b).

2.3.4.2 **Assessment.**

Dummett (1987) suggests that a systemic assessment is essential to determine a person's progress, assess the person's needs and design an appropriate programme and act as an index to effectiveness of treatment of the individual. Occupational therapists assess their patients to establish a baseline against which improvement can be measured (Thompson and Morgan 1990). This also helps decisions to be made with patients regarding priority areas for treatment (Law and Letts 1989, Thompson and Morgan 1990, Mulley 1985 and Smith and Tiffany 1988). Other functions of the evaluation process include giving some indication of potential to change, enlisting the cooperation of patients in beginning to assess their capabilities and needs, and helping patients begin a course of action designed to master some of the difficulties they have previously tried to master alone (Smith and Tiffany 1988).

The following list shows the areas assessed:

- activities of daily living (Turner 1981, Eggers 1983, Mulley 1985, Warlow 1987, Curry and March 1988,

Thompson and Morgan 1990, Pedretti 1990 and Eakin 1991b);

- motor function (Peszczynski et al 1972, Sahs 1979, Eggers 1983, Mulley 1985, Curry and March 1988, Thompson and Morgan 1990, and Pedretti 1990);
- sensory function (Peszczynski et al 1972, Sahs 1979, Eggers 1983, Mulley 1985, Curry and March 1988, Thompson and Morgan 1990, and Pedretti 1990);
- perceptual skills (Eggers 1983, Mulley 1985, Curry and March 1988, Thompson and Morgan 1990, Pedretti 1990 and Eakin 1991b);
- cognitive skills (Peszczynski et al 1972, Sahs 1979, and Pedretti 1990);
- social skills (Mulley 1985 and Curry and March 1988);
- work skills (Mulley 1985, Warlow 1987, Curry and March 1988 and Pedretti 1990);
- leisure skills and interests (Mulley 1985 and Curry and March 1988);
- other specific assessments such as, of chair and wheelchair requirements and splinting requirements (Mulley 1985 and Curry and March 1988).

2.3.4.3 **Interventions.**

Occupational therapists have developed treatment procedures for rehabilitation of stroke from the use of creative activity for specific physical and psychological

benefits, the use of group therapy within structured environments, the adaptive and remedial use of activities of daily living, and the inclusion of techniques to maximise neuropsychological functioning (Wilcock 1986).

The major components of intervention currently used by occupational therapists include evaluation and retraining of:-

- perceptual and cognitive skills;
- activities of daily living;
- sensory motor abilities by neurophysiological developmental or functional approaches;
- affective and social skills by structured group therapy for education, relaxation, support, and counselling;
- vocational skills;
- maintenance therapy through appropriate use of community agencies (Wilcock 1986).

a) **Facilitating Independence in Activities of Daily Living.**

Activities of daily living are tasks of self-maintenance, mobility, and home management that enable individuals to achieve personal independence in their environment (Pedretti 1990b).

The most common tasks of activities of daily living are:

- mobility including movement in bed, wheelchair mobility, transfers, indoor mobility with special equipment, outdoor mobility with special equipment and use of public or private transport;
- self-care including dressing, feeding, toileting, bathing, and grooming;
- management of the environment including ability to use telephone, keys, taps, light switches, windows and doors;
- communication including ability to write, read, type, use the telephone and a special communications device;
- home management including shopping, meal planning and preparation, cleaning, laundry and operating household devices (Pedretti 1990b and Reed 1984).

Reed (1984) suggests that the importance of activities of daily living can be summarised as follows:

- performance of activities of daily living is central and basic to the goal of achieving independent functioning;
- the more independent a person is in activities of daily living, the more likely the person is to be able to maintain independent living;
- there is a core of activities which a person must be able to perform alone in order to live independently;
- the performance of activities of daily living is a

functional measure of the success of a rehabilitation programme.

Eakin (1991a) and Gresham (1990) also agree that independence in activities of daily living is one of the most important and most frequently used measures of outcome in studies of stroke.

The role of occupational therapy in activities of daily living is to assess ADL performance skills, determine problems that interfere with independence, determine treatment objectives, and provide training or equipment to enhance the achievement of a higher level of independence (Pedretti 1990b and Reed 1984). Intervention techniques include basic teaching methods such as forward or backward chaining and the use of adapted devices within the teaching sequence (Reed 1984). The need to learn new methods or use assistive devices to perform ADL may be temporary or permanent, depending on the particular dysfunction and the prognosis for recovery (Pedretti 1990b).

An aid or assistive device provided by occupational therapists, is a specially designed item of equipment intended to facilitate an activity - a tool for living (Moy 1987). They range from simply a knife with an enlarged handle to the complexities of electronic

environmental control systems.

Parker and Thorslund (1991) carried out a study in Sweden to look at the use of technical aids among community-based elderly. They assessed 57 patients who had one or more technical aids and found 29% of the aids were for mobility (for example, sticks, frames and wheelchairs); 20% for communication (for example, hearing, telephone); 16% for environmental adaptations (for example, cushions, grab rails); 5% orthoses/prostheses and 11% other (for example, eating aids, reachers, special scissors). They found that 75% of the aids were being used, and that 74% of the patients had an aid that granted autonomy. If these people did not have the aid they would need more personal assistance. They conclude that the provision of technical aids by occupational therapists can influence the independence of the elderly.

In his study comparing stroke units with medical units Garraway (1982) found that 82 per cent of stroke unit patients received aids compared with 56 per cent of medical patients.

b) **Neurophysiological Approaches:**

Collin (1975) believes that neurophysiological techniques should form an essential part of the occupational

therapist's treatment of the neurologically impaired adult. Theories and rationales for intervention which may modify dysfunction have been developed, many by physiotherapists. Some occupational therapists have included techniques from these approaches in their treatment programmes to enhance patients' functional achievement and to reinforce sensory motor retraining by repetition and continuity of treatment approaches (Wilcock 1986). Each of these methods has its own specific treatment principles, which have been developed in accordance with the way in which the founder saw the problems and which ones they emphasised (Eggers 1983).

The Rood approach was developed by Rood, an occupational and physical therapist (Wilcock 1986). The approach is based on the assumption that any motor deficit is a loss of a function that was acquired during normal sensorimotor development (Liberman 1986). This method utilizes cutaneous sensory stimulation to modify muscle tone and voluntary motor activity and uses brushing, icing, tapping, pressure and stretch reflexes (Hagedorn 1992).

The Bobath approach was developed for cerebral palsied children and adult hemiplegia after the Second World War (Eggers 1983). The concept of the Bobath approach, deals with patterns of coordination and involves the patient's

sensory, perceptual and adaptive behaviour as well as motor problems (Bobath 1990).

With this method, abnormal posture and movement patterns are inhibited and therefore spasticity is reduced and normal movement sequences may be facilitated (Eggers 1983). This aims to improve the quality of movement on the affected side, so that ultimately the two sides work together as harmoniously as possible within the scope of cerebral injury (Bobath 1990).

Proprioceptive Neuromuscular Facilitation (PNF) was first developed by Kabat and expanded by Knott and Voss (Wilcock 1986). PNF is a technique which uses positioning and patterns of movement in developmental sequence and emphasizes sensory input, visual cues and verbal commands to produce maximum input (Hagedorn 1992).

While all these techniques are slightly different (Pelland 1986), they have some common features:

- using sensory input to facilitate or inhibit motor function;
- utilizing the sequence of normal human motor development in treatment;
- understanding the critical role of reflex activity in the facilitation of inhibition of voluntary motor activity;

- utilizing multiple motor repetitions in the programme;
- integrating the affected side of the body with the body as a whole;
- stressing the importance of therapist - patient interactions.

Approaches and techniques used differ from service to service (Wilcock 1986). Very few controlled trials have assessed outcomes using the various approaches. Wade et al (1985a) suggests that most therapists probably adopt a pragmatic approach, using methods which they have found to work, and avoiding methods which they do not like. Chin (1982) describes a survey of the techniques used in 30 therapy departments in the north of England which found that more than 90% of therapists used a combination of conventional functionally orientated exercises and facilitation exercises.

Collin (1975) suggests that a combination of the techniques of Rood and Bobath appear to be the most effective methods of treating most neurological conditions. However Eakin (1991a) reports that one particular approach to treatment has not been demonstrated to be more successful than any other.

c) **Retraining of perceptual and cognitive skills.**

Most occupational therapists use what is known as the functional approach to the treatment of perceptual deficits because it is more practical and more understandable to the patient (Siev et al 1986). The emphasis is on treating the symptoms rather than the cause of the problem, for example, patients with spatial relations and body-image problems will have difficulty dressing themselves; with practice, patients will learn to dress but will still have the spatial relations, and body image problems (Thompson and Morgan 1990).

The functional approach can be divided into two aspects (Thompson and Morgan 1990):

- compensation, where patients is made aware of their problems and then taught to compensate or make allowances for them;
- adaptation, where the environment of patients are changed to help patients compensate for their symptoms.

Siev et al (1986) also suggest that a sensory integrative approach or a transfer of training approach may be used for the treatment of perceptual dysfunction. The transfer of training approach assumes that the practice in tasks requiring specific cognitive and perceptual-motor skills will generalise, and lead to improved ability in other

activities with similar cognitive-perceptual requirements (Wilcock 1986). Wilcock (1986) suggests that any of the approaches, by demanding active participation of patients in thinking about, and executing sequential planned activity, should assist in cognitive and perceptual processes. Therapists need to be constantly monitoring the sensory, motor and cognitive experience and patient responses, changing input if response is undesirable.

d) **Retraining of Work Skills.**

Only a small proportion of stroke patients return to the work force because many are beyond working age and have already retired, and others have residual impairment which prevents them returning to a previous field of employment (Wilcock 1986).

The occupational therapist's role in work rehabilitation and assessment involves identification of work potential and the development of the essential skills required to compete for employment (Bumphrey 1987 and Wilcock 1986). If possible a detailed job description should be taken of the requirements of the job in order to assess whether patients are likely to be able to return to work. By careful involvement, realistic assessment and successful placements, occupational therapists can play an important role in helping employers to understand more fully the

needs of disabled people and encouraging them to widen the range of opportunities open for them, as well as ensuring that the disabled person is aware of his real skills and has the confidence of applying them in a work situation (Bumphrey 1987).

For those who wish to return to some form of employment but do not appear to have that potential to return to a previous or new job, a sheltered workshop or voluntary occupation may be suitable (Wilcock 1986). Alternatively, occupational therapists may help patients to explore the possibilities of self or homebound employment, perhaps on the basis of previous skills or leisure interests which are still possible despite stroke, or using new skills learned during rehabilitation.

e) **Resettlement into the Community.**

To ensure that patients are safe and independent in the community, occupational therapists may prepare patients for going home by carrying out a pre-discharge visit. They provide aids as necessary and appropriate, and liaise with community services regarding structural alterations and other environmental changes (Mulley 1985). Joice and Coia (1989) note that occupational therapists are almost the only and certainly the main profession employed in both health and social services departments

and therefore this should confer some benefit when conducting resettlement into the community.

In the final stages of treatment, patients resume or assume occupational roles in their living environment and in the community (Pedretti and Pasquinelli 1990). Appropriate tasks of self-care, work, education and play and leisure are performed to patients' maximum level of independence.

Soderback et al, (1991) in a study looking at levels of function and activity three years after stroke, found more individuals thought they had changed life satisfaction and leisure activities and social roles than those with changed personal care, housework, and gardening. Soderback et al (1991) maintain this indicates a need for occupational therapy which focuses on leisure activities and life satisfaction.

Occupational therapists encourage the re-establishment of previous or the development of new recreational and community interests wherever possible (Wilcock 1986). Leisure and social activities can play an important part in the overall rehabilitation process, whether a patient returns to work or not (Thompson and Morgan 1990). Occupational therapists should look at patients' leisure activities particularly as unemployment is high and as

people are retiring earlier and living longer (Mayers 1990).

Hopson et al (1983) suggest that in the area of leisure occupational therapists aim to:-

- provide all patients with the opportunity to relax and enjoy themselves;
- encourage participation with others, concentration, memory and orientation;
- combine physical and proprioceptive skills through certain games played in a seated position, for example, carpet bowls;
- ease tension and encourage a competitive spirit with team activities;
- help patients and their relatives plan towards discharge,and therefore encourage personal interests which can be pursued at home;
- offer advice regarding potentially suitable leisure pursuits for individuals.

Leisure activities that patients have enjoyed prior to stroke may be of great value in motivating participation and in redeveloping sensory motor and cognitive skills (Wilcock 1986). As a general rule disabled people need a lot of practical help and encouragement to get started with a leisure activity (Wilcock 1986, Western 1987). Occupational therapists can help by providing this

encouragement and support (Western 1987). They can also make realistic suggestions of possible activities that are practical, achievable and acceptable to the person concerned.

Occupational therapists may need to assist with practical problems such as access to community resources or difficulties of carrying out former activities because of impairment (Wilcock 1986). If patients are unable to follow previous interests, the need for activity and involvement outside the home may be met by use of special agencies such as day activity centres.

2.3.5 PROVISION OF OCCUPATIONAL THERAPY SERVICE.

Patients are referred to occupational therapy when they, or others responsible for their care, perceive that they are not adequately performing their activities of daily living (Trombly 1989). Allen et al (1988) and Wilcock (1986) suggest that all patients with any physical disability should be referred to a physiotherapist and an occupational therapist as soon as possible.

Mulley (1985) suggests that the belief that occupational therapists are "bountiful ladies who encourage unwilling captive patients to weave baskets" is one of the most tenacious myths in rehabilitation medicine. Mulley (1985)

also suggests that it might explain why many stroke patients in hospital are referred late or not at all to the occupational therapy department. Joice and Coia (1989) suggest that some degree of ignorance exists as to the full extent of the skills that can be provided by occupational therapy.

In a survey (Brocklehurst et al 1978b) in Manchester, it was found that only a quarter of stroke patients were seen by an occupational therapist. In his study comparing stroke units with medical units Garraway (1982) found that 66% of all patients in stroke units had begun occupational therapy within one week whereas only 18% of admissions to medical units had. Garraway et al (1980a) also found that almost all patients admitted to the stroke unit received occupational therapy while only 47% of the patients admitted to the medical unit received occupational therapy.

Wade et al (1984b), in a study investigating the amount of physiotherapy and occupational therapy given to acute stroke patients over the first 6 months, concludes that patients in general receive very little therapy while attending the rehabilitation unit in relation to the total amount of time that they are awake, that the major factor influencing the amount of therapy given is the severity of

the stroke and that more attention should be given to the content of therapy rather than the amount.

Ostrow et al (1989) found that patients who received occupational therapy as part of their rehabilitation programme were more likely to be discharged to home environments. This result occurred despite the fact that patients receiving occupational therapy were rated as more severely impaired than patients who did not receive occupational therapy as part of their rehabilitation program.

Despite that fact that there are no reliable randomized controlled trials which study the effectiveness of occupational therapy as a treatment (Effective Health Care Bulletin 1992), Reed and Sanderson (1983) outline the value of occupational therapy to both an individual and a community. As a result of occupational therapy patients may see the value of occupational therapy in terms of;

- increased ability and capacity to do and perform various daily tasks;
- change in the organisation of when and how tasks are done, which permits more to be accomplished or leaves more time for self selected activities;
- increased sense of accomplishment, satisfaction and control over one's own life and fewer feelings of dependence and hopelessness;

- increased ability to get around the house and community safely because architectural barriers have been removed or specialized equipment has been installed;
- improved level of physical and mental health and sense of well-being due to the increased ability to perform, organise and fulfil those social demands and individual needs which occur in the process of living.

A community may gain some or all of the following from having an occupational therapy service (Reed and Sanderson 1983):

- a greater number of individuals who are more able to perform daily tasks for themselves and thus require less expensive help from others;
- increased productive potential because the injured or ill person is able to return to work, is able to work for the first time, or is able to contribute in unpaid service, such as voluntary work;
- a decrease in the number of individuals who feel hopeless or helpless and may have been using many hours of a physician's or other service person's time for very little constructive purpose;
- a safer community which is accessible to all because barriers have been reduced or eliminated;
- a healthier community because more people are aware of the relationship of performance capacity to physical and emotional well-being;

- an increased sense of commitment to the quality of life as well as the quantity of life through recognition that dignity and self worth are part of the rights of each individual regardless of individuals limitations.

2.3.6 SUMMARY

Occupational therapists are members of the multidisciplinary team who contribute to the rehabilitation of stroke patients. Occupational therapy is based on the philosophy that man is an active being whose development is influenced by the use of purposeful activity.

The goal of occupational therapy with stroke patients is to facilitate maximum recovery of function. After assessing the patient's needs, the occupational therapist uses techniques such as neurological approaches, to retrain patients in skills necessary for a full life including activities of daily living, sensory, motor, perceptual, social and vocational skills.

In order to establish the needs of the patients and monitor improvements, the occupational therapist and other members of the multidisciplinary need to use standardized assessments. Measurements of disability and handicap are

available for all aspects of patients' lives. A number of these are described in the next chapter.

CHAPTER 3.

EXPERIMENTAL MATERIALS

MEASUREMENT TOOLS OF DISABILITY AND HANDICAP

3. EXPERIMENTAL MATERIALS - MEASUREMENT TOOLS OF DISABILITY AND HANDICAP.

Many reasons have been given to support the use of measurements of disability and handicap. A disability is defined by the World Health Organisation as any restriction or lack of ability to perform an activity in a manner or within a range considered normal for human beings and reflects the consequences of impairment in terms of functional performance and activity by the individual (WHO 1981:p8). A handicap, according to the World Health Organisation, is a disadvantage, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal for that individual and reflects interaction with and adaption to the individual's surroundings (WHO 1981:p8).

Practitioners require tools which, in addition to their simplicity and sensitivity, give results which are easily communicable to others (Gibbon 1991). A measurement tool can serve to give direction to the rehabilitation process and facilitate the devising of both short and long-term goals when planning care (Gibbon 1991). A systemic assessment is essential to determine patients' progress, assess patients' needs and design an appropriate programme and act as an index to effectiveness of treatment of the individual (Dummett 1987).

The King's Fund (1988) consensus conference on stroke recommended that assessment, using standard tools, should be undertaken on all patients at regular intervals and the results should be recorded in patients' medical notes. Simple measures which are reliable, relevant and valid should be incorporated into the records of all patients referred for specialist rehabilitation (Collin 1991 and Wolfe et al 1991).

Measurements can be used to evaluate treatment and the outcome of treatment. Murdock (1992) suggests that new techniques, or those which have not been evaluated, must be assessed objectively. As there is usually a strong desire to discover effective treatments, Sunderland (1990) and Murdock (1992) suggest that by using measurement tools steps are taken against wishful thinking influencing the results collected or the interpretation placed on them.

The instructions for a measure should be clear and concise to expedite use (Law and Letts 1989). The scoring system should be straight forward and quick but with results that can be applied to programme planning or the evaluation of clients (Law and Letts 1989).

Several suitable instruments are available to measure disability (Gladman 1991). There are assessments available to measure activities of daily living, leisure

activities, social function, mood, quality of life and life satisfaction, perceptual problems and the burden of caring. Some of these are standardised and have been tested for validity and reliability.

Validity implies that a test measures what it is designed to measure (Burton 1989). Its findings are not distorted by a factor which has not been eliminated or controlled (Burton 1989). Responsiveness to change is the most essential validation evidence required for the use of ADL measures as evaluation tools (Law and Letts 1989).

Reliability of an assessment tool can refer to test-retest reliability or inter-rater reliability (Burton 1989). Test-retest reliability is the consistency of test results on repeated testing over time. If a test has high inter-rater reliability, different testers will produce the same test results when testing the same patient (Burton 1989).

Standardisation depends on extensive testing on the normal population to establish the average or mean score, and the range of scores above and below the mean (Burton 1989). Normal range is considered to be two standard deviations (Burton 1989). Standardisation of the assessment process is a means of removing some of the variables (possibles sources of unwanted influence) from the test environment by formalising instructions, the presentation and

positioning of test materials, and the sequence of test items into a protocol that is never changed. These procedural arrangements may improve inter-rater reliability, and are essential for accurate comparisons of pre-treatment and post-treatment assessments (Burton 1989).

Occupational therapists use measurements to describe the client's problem, to formulate a prognosis, and to evaluate the effects of occupational therapy (Law and Letts 1989 and Murdock 1992).

3.1 ACTIVITY OF DAILY LIVING SCALES.

Stroke results in a wide range of disabilities, making comparisons between patients difficult, but the functional consequences can be assessed using activity of daily living scores (Wolfe et al 1991). Many instruments for assessing activities of daily living (ADL) have been developed.

The most commonly used, and those described here, are the Barthel ADL Index, the Katz ADL Index, the Northwick Park Index of Independence in ADL, the Nottingham Ten-point ADL Index and the Rivermead ADL Scale.

An ADL measure can vary from a self-administered form, to an interview format, to the scoring of actual performance (Law and Letts 1989). Assessment of activity of daily living skills is usually accomplished by using a check sheet to record performance (Reed 1984). Several types of assessments are available, each having limitations in relation to what and how items are measured. Law and Letts (1989) recommend that no further ADL scales are developed, but that research should aim to improve and validate existing scales.

Instruments to measure activities of daily living quantify information for one of three purposes (Law and Letts 1989):

- a descriptive ADL instrument presents a picture of a person's status at one point in time; the results allow comparison with other persons;
- a predictive ADL instrument sets criteria against which a person's status is compared;
- an evaluative ADL scale measures a person's status over time to evaluate any change in ADL function.

If the ADL instrument used is an ordinal scale, it cannot be presumed that there is an equal distance in terms of function between scores of 1 and 2 and scores of 3 and 4. Two people can each achieve the same total score but have different patterns of ADL disability (Law and Letts 1989).

There is an increasing awareness among occupational therapists of the need to define and standardise the concept of activities of daily living (Murdock 1992). The quickest and easiest way for occupational therapists to establish better methods of assessment is to make use of those ADL assessments which have already been published and which provide evidence of their reliability and validity (Eakin 1989).

3.1.1 The Barthel Activities Of Daily Living Index.

In 1965 the Barthel ADL Index was developed by Mahoney and Barthel, as a simple index of independence to score the ability of patients to care for themselves, and by repeating the test, to assess their improvement (Mahoney and Barthel 1965). It contains 10 items and has both a self care and a mobility component (Bacher 1990). Self-care includes items related to eating, grooming and toileting; the mobility component contains items related to transfers and ambulation.

The original scoring system was from 0 to 100, this has been modified so that scores range from 0 to 20 with higher scores signifying better functioning (Collin et al 1988, Bacher 1990). It is not hierarchical and therefore does not result in a total score that gives a clear indication of the level of disability (Gibbon 1991).

Granger and Hamilton (1990) found that no specific cut-off score could, by itself, be regarded as adequately specific or sensitive to be used as the sole criterion for admission for rehabilitation services or as the sole criterion for discharge.

Rodgers et al (1993) suggest that the Barthel ADL Index is most useful in assessing patients who are moderately or severely disabled. There is a ceiling and flooring effect, meaning that those scoring maximally may still be significantly handicapped with the potential of improvement beyond the limits of the scale. As a result the Barthel ADL Index lacks sensitivity to change in its upper and lower ranges (Rodgers et al 1993). To overcome this patients with high Barthel scores should subsequently be assessed with an instrumental ADL scale.

The index has been shown to be reliable under several different conditions - formal research, clinical practice, by post and over the telephone (Wade 1992). While looking at how the information is collected Collin et al (1988) found that the method of obtaining the information does not seem to be important, i.e. by self-report, informed nurse or carer, or trained observer. However, Collin et al (1988) and Ranhoff and Laake (1993) found that allowances need to be made for confused patients, confirming their replies with nurses or relatives if there is any doubt

about the patient's cognitive ability to give correct answers. It has also shown adequate observer and test-retest reliability and has measured changes in ADL after intervention in controlled research (Law and Letts 1989).

The Barthel ADL Index has been used in many studies involving stroke patients. Many investigators have used the Barthel scale to characterize individuals and groups of patients to measure change over time to compare results of rehabilitation interventions (Granger and Hamilton 1990). Freidman (1990) introduced a new system of stroke patient management based on Barthel activities of daily living scores. He found that by using the scores in patient management decisions, it appeared to reduce the length of stay and hasten functional recovery without greatly influencing final functional state. Those with scores of 0-1 seven days after stroke were too impaired to participate or benefit from rehabilitation whereas those with a Barthel score of 19-20 were generally suitable for early discharge home. Granger et al (1988) suggests that a score of 12 or more at the time of discharge from rehabilitation is associated with a greater likelihood of living in the community six months after discharge.

Chino (1990) found the Barthel ADL Index a useful tool for evaluating activities of daily living function of stroke patients in different countries where people's

lifestyles are dissimilar such as in Japan, America and Great Britain.

3.1.2 The Katz Activities of Daily Living Index.

The Katz ADL Index is an ordinal scale that scores on 6 functions - bathing, dressing, going to the toilet, transferring, continence and feeding; cases are ranked from A (most independent) to G (most dependent) with those not meeting the classification criteria designated as 'other' (Gresham et al 1980). It does not include walking, in contrast to other ADL indices (Wade 1992).

It was developed as a survey instrument to give an objective guide to the course of chronic illness (Eakin 1989) and was designed in order to describe, for clinical purposes, the states of elderly patients (Bowling 1991). It is based on the premise that abilities return in a predictable order (Wade 1992). It has a high predictive validity regarding early outcome in terms of length of hospital stay and survival or death within the first month after an acute stroke (Asberg and Nydevik 1991).

It has been used extensively with institutionalised populations to assess clinically significant changes in function over time (Eakin 1989). The index has been used mainly in American studies and with elderly disabled

people (Eakin 1989) but it can be used with any condition (Wade 1992). The Katz Index of ADL has also been used in Swedish studies. Asberg and Nydevik (1991) found that it can serve as a reproducible and valid tool for early prognosis of stroke outcome, thereby facilitating the planning of care and rehabilitation both in hospital and in primary health care.

3.1.3 The Northwick Park Index of Independence in Activities of Daily Living.

The Northwick Park Index of Independence in ADL was developed as a method of assessment of activities of daily living for the needs of a large randomized controlled trial of therapy late after stroke (Benjamin 1976). Its aims were to be comprehensive in coverage yet short and concise, simple enough to be performed by the normal unimpaired adult and suitable to assess any degree of disability. With this in mind it was constructed so that it can be used for reassessment and be objective (Benjamin 1976). Activities assessed include mobility, self-care and domestic activities and such instrumental activities which are relevant to the community, for example, preparation of tea, use of cooker and outdoor mobility. It includes more items and activities than most (Wade 1992).

The Northwick Park Index of Independence in ADL has been tested for reliability and validity (Eakin 1989). It has been developed for long term use (up to 12 months) and it has been used in the community as well as in the hospital setting (Eakin 1989).

3.1.4 The Nottingham Ten-point Activities of Daily Living Index

The Nottingham Ten-point ADL Index was constructed by Ebrahim et al in 1985 for use with stroke patients. It is a hierarchical activities of daily living scale for stroke patients comprising a 10 point scale measuring basic self-care activities (Wade 1992). It is appropriate for measuring functional recovery of stroke patients in hospital and those recently discharged and is a useful tool for comparing outcome between patient groups in acute stroke trials (Wade 1992). It can be administered by observation, interview or post (Gibbon 1991).

Ebrahim et al (1985) found the Nottingham Ten-point ADL Index to be reliable and repeatable. They also found that agreement between postal and direct ADL assessments were good enough for classifying patients into functional groups.

Barer (1989) used it to investigate the relationship between functional recovery and length of stay in hospital. The predictability of the course of functional recovery using the 10 point scale allowed reliable estimates to be made of the ADL score at discharge.

3.1.5 The Rivermead Activities of Daily Living Index.

The Rivermead ADL Index is a ranked scale, constructed so that if patients fail successive tests on individual items, no further tests need to be carried out (Eakin 1989). Each of the 31 items are scored on a 3 point scale - dependent, independent with verbal supervision and independent (Eakin 1989). It contains 3 sections, one covering self-care, and two covering household activities. It was developed to evaluate patients' progress for clinical and research purposes and can be used to assess recovery of abilities of patients following strokes (Gibbon 1991).

The self care section is valid as a measure of recovery and reliable, both between raters and over time. The assessment has been tested for reliability and validity, though with some reservations about the household section (Whiting and Lincoln 1980). It has not been widely used in other studies though Lincoln and Edmans (1990) carried out a study designed to validate the scale for patients

aged over 64 years. They suggested a revised order of assessment based on the order of difficulty of items.

The Rivermead ADL Index was revised in 1990, the revised version having the same items but scores each item as independent (=1) or needs help (=0), has amalgamated the two household sections, and has a different order of items (Wade 1992). This version has increased reliability by simply using each item as a pass-fail item (i.e. without an intermediate grade) (Wade 1992).

3.1.6 The Ideal Activity of Daily Living Scale.

Each of the various scales have advantages and disadvantages though there is, as yet, no ideal scale. Table 3.1 indicates the aspects of daily living assessed by each scale.

For a descriptive, diagnostic measure, that is, presenting a picture of a person's status at one point in time, the Barthel ADL Index and Katz ADL Index have good reliability and validity evidence (Law and Letts 1989). Both are short and appear to discriminate among levels of ADL function and their results allow comparison with other patients.

The Barthel ADL Index and the Katz ADL Index have the ability to predict function against other standards (Law and Letts 1989).

Table 3.1 Contents of ADL scales.

Content	Barthel	Katz	Northwick	Nottingham	Rivermead
Bathing	Yes	Yes	Yes	Yes	Yes
Continence	Yes	Yes	Yes	No	No
Cooking	No	No	Yes	No	Yes
Dressing	Yes	Yes	Yes	Yes	Yes
Drinking	No	No	No	Yes	Yes
Feeding	Yes	Yes	Yes	Yes	Yes
Grooming	Yes	No	Yes	Yes	Yes
Household activities	No	No	No	No	Yes
Leisure activities	No	No	No	No	Yes
Making hot drink	No	No	Yes	Yes	Yes
Mobility	Yes	No	No	Yes	Yes
Toilet use	Yes	Yes	Yes	Yes	Yes
Transfers	Yes	Yes	Yes	Yes	Yes
Undressing	No	No	No	Yes	Yes
Use of taps	No	No	Yes	No	No

An evaluative ADL scale measures a person's status over time to evaluate any change in ADL function. The Barthel ADL Index is the best instrument for responsively

measuring change in ADL function (Law and Letts 1989). Despite this, Granger and Hamilton (1990) suggests that there has been resistance to the Barthel ADL Index's universal use based on clinicians' perception that not enough domains are covered to account for the potential impact of rehabilitation interventions and that the grading system at 3 or 4 levels is not sufficiently sensitive to reflect change, particularly item by item over the short run. Wade (1988b) argues that it is sufficiently sensitive for routine clinical purposes, but has possible limitations in the context of research.

For the purposes of this study the assessment selected had to be a simple test, easy to complete, one that measures change over time but also one that had been validated for use in stroke research and, in particular, suitable for use by post. Despite their advantages these criteria excluded the Katz ADL Index, the Northwick Park Index of Independence in ADL and the Rivermead ADL Index (Table 3.1). The Katz ADL Index had not been validated for use in stroke research. As the Rivermead ADL is long and comprehensive it would not be suitable to use by post. The Northwick Park Index of Independence in ADL has several advantages in that it has published evidence of tests for reliability and validity, it has been developed for long term use (up to 12 months) and it has been used in the community as well as in the hospital setting (Eakin

1989) but it was also excluded because it had not been validated for use by post.

Both the Nottingham Ten-point ADL Index and the Barthel ADL Index are simple to use and score, reliable and have been tested for postal use. The one disadvantage of the Nottingham Ten-point ADL Index is the fact that it does not measure continence. Incontinence is one of the consequences of stroke and is present in 11 per cent of patients at six months (Ebrahim 1990) and is therefore important to measure.

The Barthel ADL Index has been chosen for use in this study because it has been used in more research than any other ADL measure (Collin 1991); it has been compared favourably with more complex and detailed measures (Collin 1991 and Wolfe et al 1991); it is sensitive to change (Gresham et al 1980); it is amenable to statistical analysis (Gresham et al 1980); it is a good measure and worthy of universal use (Wade 1986 and Wolfe et al 1991); it is simple and quick to use (Wade 1986, Gibbon 1991 and Eakin 1993); its results can be easily understood and communicated between different professions (Eakin 1993) and its content is perceived as relevant to both clinicians and patients (Eakin 1993).

3.2 SOCIAL FUNCTION SCALES.

Scales have been developed to assess function in activities that are more extensive than personal care, such as social function and leisure activities. However, there are very few itemized scales of social function that have been used in stroke research (Wade et al 1985c). Wade et al (1985c) suggest that one major reason for this is the large number of items that could be included, and a second reason is the considerable diversity of opinion about what actually constitutes 'social outcome'. The three scales described, the Nottingham Extended Activities of Daily Living Scale, Frenchay Activities Index and the Functional Life Scale have been used in other stroke studies.

3.2.1 The Nottingham Extended Activities of Daily Living Scale.

The Nottingham Extended Activities of Daily Living Index was developed by Nouri and Lincoln (1987) to assess activities which may be important to stroke patients who have been discharged home. It has been validated for administering by post (Nouri and Lincoln 1987, Lincoln and Gladman 1992 and Wade 1992).

It is a ranked scale and the advantage of this is that all patients with the same scores are independent in the same items (Nouri and Lincoln 1987). It consists of a questionnaire of 22 activities divided into 4 groups: mobility, kitchen, domestic and leisure. Activities performed by patients on their own or on their own with difficulty were scored as 1. Activities which patients were unable to perform or for which help was needed were scored as 0 (Lincoln and Gladman 1992).

Lincoln and Gladman (1992) found that an overall score can provide an indication of overall independence sufficiently robust for use with groups. With individual patients the scaling properties are not perfect and therefore subsection, rather than overall, totals should be considered when evaluating patients' progress (Lincoln and Gladman 1992).

Towle (1988) used the Nottingham Extended Activities of Daily Living Scale (EADL) as part of a study looking at depressed mood after stroke. The study showed that the ranking of items did not reflect the order of difficulty of items for stroke patients who were depressed. The EADL was scored in terms of what patients did rather than what they were capable of. They were often capable of carrying out an activity but never actually did it (Towle 1988).

3.2.2 **The Frenchay Activity Index.**

The Frenchay Index was designed by Holbrook and Skilbeck in 1983 and is a questionnaire type assessment which relates to domestic activities, leisure/work activities and outdoor activities. It records the frequency with which a patient has performed various activities over the preceding months (Wade et al 1987b). It concerns those activities that have actually been performed during the previous 3 and 6 months, comprising 15 individual activities summed to give an overall score from 0 (low) to 45 (high). It is intended to measure activities which are not essential to functional independence but which reflect a higher level of independence and a more "social survival" (Wade et al 1987b).

The Frenchay Activity Index is considered valid, sensitive, reliable, simple, communicable and relevant (Wade et al 1985c). It is short and simple to administer (Eakin 1989) and has been used in clinical research (Wade 1992).

3.2.3 **The Functional Life Scale**

The Functional Life Scale was developed by Sarno et al (1973) and was one of the first scales of social function (Wade et al 1985c). It measures 44 different functions

grouped into five categories: cognition, ADL, home activities, outside activities and social interaction (Wade et al 1985c).

This scale was designed for use on patients at home, and assesses what patients actually do and not their potential performance (Wade et al 1985c). Each activity is rated by an assessor on up to four aspects as appropriate: self-initation, frequency, speed and overall efficiency, there being a fifth category for 'not applicable'. Each of these aspects in turn is scored between 0 (not done at all) to 4 (done normally). The scale can then be analysed in many ways; simple total; scores for each section; simple total scores for each aspect; adjustment to take account of activities that are not applicable etc (Wade et al 1985c).

Preliminary analysis of the scale suggests that it is reliable and valid, but it has not achieved widespread use (Wade et al 1985c).

3.2.4 The Ideal Social Function Scale

Table 3.2 shows the contents of the three scales. The criteria for the most suitable social function scale for this study were similar to those for an ADL assessment, that is, a simple test, easy to complete, one that

measures change over time but also one that had been validated for use in stroke research and, in particular, suitable for use by post. Both the Frenchay Activity Index and the Nottingham Extended Activities of Daily Living Index fulfilled a number of these criteria.

Table 3.2 Contents of social function scales.

Content	Extended ADL	Frenchay	Functional Life
Mobility	Yes	Yes	Yes
Climb stairs	Yes	No	No
Use public transport	Yes	Yes	Yes
Make hot snack/drink	Yes	Yes	Yes
Do shopping	Yes	Yes	Yes
Read newspaper/books	Yes	Yes	Yes
Use telephone/letters	Yes	No	Yes
Go out socially	Yes	Yes	Yes
Manage garden/D.I.Y.	Yes	Yes	Yes
Drive a car	Yes	Yes	No
Housework	Yes	Yes	Yes
Pursue hobby	No	Yes	Yes
Gainful work	No	Yes	Yes
Cognition	No	No	Yes
Basic self care	No	No	Yes
Attends events	No	No	Yes

The Frenchay Activities Index has one main disadvantage in that it requires respondents to have a good memory for events over the previous 6 months (Lincoln and Gladman

1992). This may be a problem for an elderly population and therefore the test is likely to be unreliable (Lincoln and Gladman 1992). The main disadvantage of the Functional Life Scale is that it takes a considerable time to assess a single patient fully, and almost as long to analyse and process the answers (Wade et al 1985c). Also no work has been done to show if it is suitable for use by post.

The Nottingham Extended Activities of Daily Living Index was chosen for use in this study. It is the only instrumental ADL assessment specifically designed for postal surveys, which makes it easy and inexpensive to use (Lincoln and Gladman 1992). Lincoln and Gladman (1992) found it appropriate for research into the evaluation of rehabilitation procedures (Lincoln and Gladman 1992).

3.3 MULTIDIMENSIONAL SCALES.

Some scales, such as the Mini Mental State Examination and the Clifton Assessment Procedures for the Elderly, cover several different aspects of patients mental status and are therefore described as multidimensional scales.

3.3.1 The Mini Mental State Examination.

The Mini Mental State Examination (MMSE) was developed by Folstein et al (1975) as a simple cognitive examination.

It was originally developed as a screening instrument of cognitive impairment among a psychiatric population (Folstein et al 1975) and is now widely used among the elderly (Wade 1992).

The MMSE is a 16-item questionnaire which is divided into two sections, the first covers orientation, memory and attention, the second tests ability to name, follow verbal and written commands, write a sentence spontaneously and copy a complex polygon (Folstein et al 1975, Bacher 1990 and Phipps 1991). It excludes questions concerning mood, abnormal mental experiences and the form of thinking (Folstein et al 1975).

It takes five to ten minutes to complete and is easy for a clinician to administer at the bedside (Folstein et al 1975 and Bridges and Goldberg 1986). It is scored out of 30 (Bacher 1990). A score below 24 is taken to indicate probable cognitive impairment (Bridges and Goldberg 1986 and Wade 1992). Dick et al (1984) and Bridges and Goldberg (1986) conclude that the MMSE is a valuable, consistent and rapid method for a routine bedside assessment of the cognitive deficit. They suggest that further refinement in areas of language and visuo-spatial function may improve its value.

The MMSE has a high degree of test-retest reliability and inter-rater agreement (Bacher 1990) and is a standard tool that has been found to be valid and reliable (Folstein et al 1975 and Phipps 1991).

3.3.2 The Clifton Assessment Procedures for the Elderly.

The Clifton Assessment Procedures for the Elderly (CAPE) are widely used in geriatric practice though they are not used much in neurological rehabilitation (Wade 1992). The test measures impairment of orientation (Wade 1992). There have not been any studies of reliability (Wade 1992). The CAPE is similar to other tests of cognitive impairment (Wade 1992).

3.3.3 The Ideal Multidimensional Scale.

The most widely used of the mental status tests is the Mini-Mental State Examination (Feher 1992). The wide popularity of the MMSE is due to its brevity (about 10 minutes) and the fact that it samples a range of cognitive functions (orientation, attention-concentration, memory, language, constructional ability) (Feher et al 1992). For these reasons, the MMSE was chosen for use in this study. It was used for assessing the patients on admission and discharge. Because the scale is not self-rating it was not suitable for use in postal form one year post stroke.

3.4 DEPRESSION SCALES.

According to Zung (1964), a depression scale should be all inclusive with respect to symptoms of the illness, it should be short and simple, it should quantitate rather than qualitate, and it should be self administered. Yesavage et al (1983) suggest that depression scales should have questions phrased in a format that would not alarm patients or make them overly defensive.

The following three assessments, the Geriatric Depression Scale, the Wakefield Depression Scale and the Zung Self-Rating Depression Scale, were considered when selecting a suitable depression scale for this study.

3.4.1 The Geriatric Depression Scale.

The Geriatric Depression Scale (GDS) was designed by Yesavage et al (1983), specifically for rating depression in the elderly. It is a reliable and valid measure of geriatric depression (Yesavage et al 1983) and is a sensitive and specific screening for depression (Brink et al 1982 and Yesavage et al 1983).

The GDS can be administered in writing or orally and has been found acceptable to the elderly (Brink et al 1985). It contains 30 questions which require a "yes" or "no"

answer (Brink et al 1985). The number of depressive responses are tallied, and the score of 0-30 indicates the level of depression (0-10 = normal; 11-20 = mild depression; 21-30 = moderate or major depression) (Yesavage et al 1983 and Brink et al 1985).

A short form of the Geriatric Depression Scale was devised to minimise problems of measuring depression in the elderly (Sheikh and Yesavage 1986). Fatigue and poor concentration can affect a measurement by making it difficult for the elderly to remain focused while filling out lengthy scales. An advantage of the Geriatric Depression Scale (short form) is that it is easy to administer and takes relatively less time to complete compared with most other scales. Sheikh and Yesavage (1986) selected 15 questions from the Geriatric Depression Scale which had the highest correlation with depressive symptoms in their validation studies. These were arranged in a 15 item, easy to understand yes/no format, similar to the regular version of the Geriatric Depression Scale. In a validation study to compare the long and short form they found both forms were successful in differentiating depressed from non-depressed subjects with a high correlation ($r=.84$, $p<.001$) (Sheikh and Yesavage 1986).

3.4.2 **The Wakefield Depression Scale.**

The Wakefield Depression Scale was designed by Snaith et al (1971), primarily for use with physically healthy young people but it has been used in several studies of stroke (Wade 1992). Although the Wakefield Depression Scales has not been validated in the elderly or in stroke, it was derived from the Zung Scales, which has been validated in stroke research (Snaith et al 1971 and Wade et al 1987b).

It is short and easy to use, but Wade (1992) suggests that it probably quantifies misery but not depression. It is useful in its ability to measure the severity of the depressive syndrome in patients already suffering from that illness (Snaith et al 1971).

The Wakefield Depression Scale consists of 12 statements to which respondents are asked to indicate degrees of agreement (Collin et al 1987). The maximum score possible is 36, a score of 15 to 18 indicates 'probable depression' and 19-36 as 'definitely depressed' (Wade et al 1987b, Collin et al 1987 and Wade 1992).

3.4.3 **The Zung Self-Rating Depression Scale.**

The Zung Self-Rating Depression Scale was devised by Zung (1964) as an attempt to quantify the symptoms of

depression. It is concerned with the varied aspects of symptomatology of depressive illness (Snaith et al 1971). It is one of the most frequently used with the elderly (Brink et al 1982).

The Zung Self-Rating Depression Scale is composed of 20 items and patients indicate the frequency with which they experience the symptom or feeling described (ie, a little, some, good part or most of the time) (Carroll et al 1973). The scale covers affective, psychological, and somatic features (Carroll et al 1973). The maximum possible score is 80, while a score of 20 indicates the complete absence of symptoms (Carroll et al 1973). A slight difficulty may arise from the wording of these graded responses because each symptom has to be considered to be present 'a little of the time', 'some of the time', 'a good part of the time', or 'most of the time' (Snaith et al 1971). Patients may sometimes have difficulty in making the necessary discriminations (Snaith et al 1971).

3.4.4 **The Ideal Depression Scale.**

Brink et al (1982) suggest that the following characteristics are necessary for the ideal depression scale for use in geriatrics: self-rating; easy to answer; geared towards geriatrics (Brink et al 1982). For the purpose of this study it was not essential that the scale

used on admission and discharge to the stroke unit was self-rating. However, in order to be included in the postal questionnaire one year post stroke, it was necessary for the scale to be both self rating and valid for use by post. The use of questionnaires to identify depression has limitations, particularly with language disordered patients (Collin et al 1987).

The Zung Self-Rating Depression Scale was not used in this study because it uses a four point scale that can be more confusing than a yes/no format and because it involves a greater number of choices and subtle discriminations that must be made by patients (Yesavage et al 1983).

The Wakefield Depression Scale was used in this study to assess patients' mood on admission and discharge from the stroke unit. It was chosen because it is short and easy to use. However it still had the disadvantage of having a four choice answer which could be confusing. For the purposes of the postal questionnaire the Geriatric Depression Scale (short form) was used. An advantage of the GDS (short form) is that it is easy to administer and takes relatively less time to complete compared with most other scales (Sheikh and Yesavage 1986).

3.5 QUALITY OF LIFE.

In its broadest sense, quality of life encompasses all aspects of human life: material and physical components, social, emotional and spiritual well-being (Fletcher et al 1992). Most interest in assessing quality of life measures has been in the evaluation of 'medical' interventions (Fletcher et al 1992).

Because quality of life encompasses all aspects of life, it is a difficult concept to measure. The following three scales, the General Health Questionnaire, the Nottingham Health Profile and Pearlman's Quality of Life were considered when selecting a scale for the purposes of this study.

3.5.1 The General Health Questionnaire.

The General Health Questionnaire was designed to assist doctors in identifying patients who are likely to have a psychiatric illness (Bridges and Goldberg 1986). It concentrates on broader components of psychiatric morbidity (particularly anxiety and depression) (Bowling 1991).

It consists of a check-list of statements asking respondents to compare their recent experience to their

usual state on a 4-point scale of severity (Bowling 1991). It is simple and quick to use (Wade 1992) and is designed to be self-administered (Bowling 1991). It can also be used to measure stress upon carers (Wade 1992).

The General Health Questionnaire is a reliable and valid measure of depression in patients (Robinson and Price 1982) and is a widely used scale (Wade 1992). Its validity when used with neurologically disabled patients has not been proven (Wade 1992).

There are three different versions of Goldberg's GHQ containing 28, 30 or 60 items (Fallowfield 1990). The GHQ-28 has four subscales assessing depression, anxiety, social functioning and physical symptoms (Fallowfield 1990). Patients underline the response that matches how they have been feeling (Fallowfield 1990). Scoring is quick and simple (Fallowfield 1990). There is a possible maximum score of 28, with high scores indicating severity of depression (Collin et al 1987). The 28-item version has an additional advantage over the other versions in that it also permits analysis within sub categories; it was developed mainly for research purposes (Bowling 1991). The shorter (28-item) version is more suitable for use with older frail people (Bowling 1991).

3.5.2 **The Nottingham Health Profile.**

The Nottingham Health Profile (NHP) was developed by Hunt and McEwen in 1980 as a survey tool (Fallowfield 1990 and Fletcher et al 1992). It is a questionnaire designed to measure social and personal effects of illness (Ebrahim et al 1986). The conceptual basis of the NHP was that it should reflect lay rather than professional definitions of health (Bowling 1991).

Over 2000 statements were derived from 768 patients with a variety of chronic ailments, and reduced to 38 statements covering six dimensions following subsequent field work (Fletcher et al 1992). It consists of two parts, the first consisting of 38 questions (each requiring a yes/no response) in the following areas: energy, pain, emotional reactions, sleep, social isolation and physical mobility (Fallowfield 1990). The second part has seven statements concerning paid employment, jobs around the house, social life, personal relationships, sex life, hobbies and interests and holidays (Fallowfield 1990).

Each statement has a weighting attached to it reflecting the perceived relative importance or severity of the item, high scores being associated with severe problems (Fallowfield 1990). The scores range from 0 (no problem) to 100 (where all problems in a section are affirmed)

(Bowling 1991) and combining its components into a total score gives the greatest accuracy in detecting depression (Ebrahim et al 1986).

The advantages of the NHP are its acceptability, short time for completion, subdivision into six scales measuring different quality of life dimensions, and availability of data on different population groups, including patients and community samples. The disadvantages of NHP are the ceiling effects of the scores, and the lack of adequate trial data to show responsiveness to less than gross forms of medical treatment (Fletcher et al 1992). Its potential as an evaluative instrument for a whole spectrum of medical intervention has not been demonstrated yet, although it might be useful in certain specific conditions such as stroke rehabilitation. It was developed for use in the community and further experience of its suitability in long-term and acute care is required (Fletcher et al 1992).

The NHP is designed for self-completion, is concise and easily administered and is the only measure of perceived health which has been extensively tested and developed for use in Europe (Bowling 1991). It can be completed in about 5 minutes. It provides only a limited measure of function, and some disabilities are not assessed at all, such as incontinence and eating problems (Bowling 1991).

This index has been well-studied for validity and reliability and used in some stroke research (Ebrahim et al 1986, Fallowfield 1990, Bowling 1991 and Wade 1992).

Ebrahim et al (1986) found that patients with high NHP scores at one month continued to report large numbers of problems at six months after their stroke. Many patients experienced pain, disturbed sleep, and social isolation, which are important, potentially treatable problems not usually considered in the management of stroke patients.

3.5.3 **The Pearlman's Quality of Life Scale.**

Pearlman and Uhlmann (1991) developed a self-administering questionnaire to assess quality of life. This global rating of quality of life is a single item in which participants consider their personal situation and rate their quality of life. It is rated on a 6-point scale: 1 - "about as good as it can possibly be"; 2 - "good enough, no major complaints"; 3 - "fair, good enough to manage"; 4 - "not so good, quality of life leaves much to be desired"; 5 - "not good at all, poor quality of life"; and 6 - "terrible, my quality of life is very bad". This test has been shown to have good test-retest reliability (Pearlman and Uhlmann 1991).

Although many facets of older patients' lives, such as impaired health and losses of external social supports, autonomy and function, may potentially diminish quality of life, Pearlman and Uhlmann (1991), in a study looking at the quality of life of elderly, chronically ill outpatients, found that these persons have adapted to their life situations in so far as they rate their quality of life as acceptable.

3.5.4 The Ideal Quality of Life Scale.

The Nottingham Health Profile (NHP) is easy to use with stroke patients and may be used with those who cannot manage more complicated mood questionnaires, such as the General Health Questionnaire (GHQ) (Ebrahim et al 1986). However, Bowling (1991) suggests that it is too short to assess the impact of a condition on quality of life and Wade (1992) suggests that it may be recording mood rather than global quality of life.

Despite the advantages of these two scales it was decided that a short measurement of global quality of life was required. For this reason the Pearlman's Quality of life scale was used.

3.6 VISUAL NEGLECT.

Most tests for visual neglect are part of a battery of tests for perception, for example, the Rivermead Battery Tests for Perception. Albert's Perception Test, described here, is an independent test for visual neglect and not part of a battery.

3.6.1 Albert's Perception Test.

Albert developed a simple, useful test for visual neglect in 1973. It consists of a series of 41 black lines, each about 2cm long, ruled on a sheet of A4 size paper. The test sheet is presented to patients, and some of the lines are pointed out to them, including those on the extreme right and the extreme left. Examiners then asks patients to cross out all the lines. Patients are encouraged to continue crossing lines until they is satisfied that all the lines have been crossed (Fullerton et al 1986).

Patients with neglect have a tendency to leave the lines uncrossed on one side of the sheet (Albert 1973, Fullerton et al 1986). If any lines are uncrossed, and more than 70% of uncrossed lines are on the same side of the midline as patients' motor deficit, a lateralised abnormality is present.

Albert's Perception Test is a straightforward, easily quantifiable test for the presence of neglect in stroke, and compliance is high even early in stroke (Fullerton et al 1986). Its quantifiable nature is especially relevant to charting progress in patients undergoing rehabilitation (Fullerton et al 1986). It would be of value as a standardised test for neglect in stroke research.

Fullerton et al (1986) found Albert's Perception Test to be a statistically significant independent predictor of both mortality and functional outcome. They found of the patients unable to complete the test, 82% were dead at six months.

3.7 CARERS' STRAIN.

Draper et al (1992) suggest that all assessments of the disabled elderly should include measures of caregiver burden.

3.7.1 The Relatives' Stress Scale.

Greene et al (1982) developed the Relatives' Stress Scale to assess the amount of stress and upset experienced by relatives as a result of having to care for the elderly. It is a simple questionnaire containing 15 items, each of which is rated 0 to 4 according to severity (Greene et al

1982, Draper et al 1992). It is simple to administer (it takes 10 to 15 minutes) and is easy to score - the higher the score the greater the burden (Draper et al 1992). It was originally developed to assess the stress of those caring for an elderly demented person living at home. Since Greene et al (1982) found that the level of cognitive functioning of patients had no influence on levels of reported stress in relatives, the scale has been used on other patient groups.

3.7.2 The McMaster Family Assessment Device.

The McMaster Family Assessment Device (FAD) was designed to assess a number of dimensions of family functioning in a form useful to researchers and clinicians (Epstein et al 1983). It is based on the McMaster Model of Family Functioning, a clinically oriented conceptualization of families (Epstein et al 1983). It evaluates seven dimensions of family functioning including problem solving, communication, roles, affective involvement, affective responsiveness, behaviour control, and general functioning (Evans et al 1987).

The 53 items in the FAD questionnaire are statements a person could make about his or her family (Epstein et al 1983). Each family member rates his or her agreement or disagreement with how well an item describes their

families. The questionnaire takes approximately fifteen to twenty minutes to complete (Epstein et al 1983).

3.7.3 The Ideal Carers' Strain Scale.

Although the McMaster Family Assessment Device has been used with stroke populations (Bishop et al 1986 and Bishop and Evans 1990), it concentrates more on family functioning rather than carers' stress; therefore it was decided to use the the Relatives' Stress Scale for this study. This scale is more suitable for assessing the amount of stress and upset experienced by relatives as a result of having to care for an elderly person. Also as it is a simple questionnaire containing 15 items it was decided that it would be easier to send to relatives/carers along with the questionnaire to the patients one year post stroke.

3.8 SUMMARY.

Measurements can be used to evaluate treatment and the outcome of treatment. For the purposes of this study it was necessary to assess patients' levels of functional competence in activities of daily living, extended activities of daily living, mood, quality of life, use of services at discharge and one year post stroke, carers' quality of life and carers' stress.

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For the various reasons already described the assessments chosen were:

- Barthel Activity of Daily Living Index;
- Nottingham Extended ADL Index;
- Geriatric Depression Scale;
- Pearlman's Quality of Life Scale;
- Green's Scale of Carers Strain.

The next chapter describes how the study was conducted and how these assessments were used.

CHAPTER 4.

METHODOLOGY

4. METHODOLOGY.

4.1 RESEARCH METHODS.

Research is an investigative process by which one attempts to find systematically, and with the support of demonstrable fact, the answer to a question or the resolution of a problem (Leedy 1989). It is directed towards greater understanding and improvement of practice over a period of time (Bell 1987).

Leedy (1989) suggests that research methodology has seven distinct characteristics:-

- research originates with a question;
- it demands a clear articulation of a goal;
- it requires a specific plan of procedure;
- it usually divides the principal problem into more manageable subproblems;
- it is tentatively guided by constructs called hypotheses;
- it will consider data in attempting to resolve the problem that initiated the research;
- it is, by its nature, circular.

Research about the outcomes of stroke is important because it monitors the impact of the disease in society, it

provides the basis for prognosis, provides a baseline to which controlled studies of interventions can be related and provides the basis for rational planning of health and human services for stroke survivors (Gresham 1986).

More and more, research is becoming a part of the everyday professional life of an occupational therapist (Ethridge and McSweeney 1970). It is the acquisition of knowledge through research, and the subsequent dissemination of this knowledge through publication, that establishes the basic literature so necessary for the acceptance of occupational therapy as a profession (Ethridge and McSweeney 1970). Brooks (1988), Royeen (1988) and Goble (1989) suggest that occupational therapists should carry out research because it is good clinical practice and it is a valuable form of quality assurance of a clinical service. It also supports the theoretical base of the profession and enables occupational therapists to define the scope of their practice and their contribution to the promotion of health and well-being in society (Fossey 1992).

A priority in occupational therapy is to develop its academic base through conduct and utilization of research (Royeen 1988). Occupational therapy can no longer justify its existence by its laws, regulations and accreditation standards. Royeen (1988) suggests that the profession

should establish itself as a science whose research verifies the use of occupation in the promotion of health and life satisfaction. Occupational therapy needs to develop a greater appreciation of and commitment to the significance of research and knowledge development (Yerxa 1987).

Research in occupational therapy is the scholarly pursuit of understanding not only about patients seen by occupational therapists, people who have extra challenges affecting adaptation, but about all people (Yerxa 1987). The study of human occupations is the basic science of occupational therapy and can be termed occupational science (Yerxa 1987 and Yerxa et al 1990). It is the study of the human as an occupational being including the need, and capacity, to engage in daily occupations in the environment over the lifespan (Yerxa et al 1990). Occupational therapy is therapeutic intervention that promotes health by enhancing the individual's skills, competence, and satisfaction in daily occupations (Yerxa et al 1990). In order to accomplish this, it applies the principles of occupational science to enable people with chronic disease or disability to act on the environment and successfully adapt to its challenges (Yerxa et al 1990).

Yerxa (1987) suggests that occupational therapists need to remove everything that is not occupation science from their research endeavours to reveal the uniqueness of occupation science. Fossey (1992) suggests that there is a need to develop a body of occupation based research as the science of occupational therapy, in order to provide a firm theoretical base for occupational therapy practice.

Knowing more about how human beings develop into occupational beings would enable occupational therapists to do a better job in reducing the incapacity of people who are considered disabled and for all people as well (Yerxa et al 1990). This science could help occupational therapists understand how to implement treatment programmes which result in greater independence and satisfaction in daily living (Yerxa et al 1990). It will enable them to improve the life opportunities of people who are disabled (Yerxa et al 1990). Through their knowledge and advocacy, new resources and better environments in which people can function as occupational beings may be provided (Yerxa et al 1990). Occupational science will underline the profound importance of the occupational therapy profession to society as a whole in the twenty-first century (Yerxa et al 1990).

Ethridge and McSweeney (1970) and Goble (1989) suggest that certain types of research are more applicable to occupational therapy, such as analytical and descriptive research. Ethridge and McSweeney (1970) believe that qualitative and ethnographic procedures are often more appropriate to the questions facing occupational therapists.

4.1.1 Analytical Research.

Analytical research helps clarify assumptions or can point out implications of various actions and uses the case-study, survey or observational techniques (Ethridge and McSweeney 1970). The study carried out by Gladman et al (1991) is an example of analytical occupational therapy research.

When conducting an analytical survey, statistical data are analysed so that meanings can be inferred, meanings that lie hidden within the data or so that potential or dynamic forces that may be clues to areas that warrant further investigation can be discerned (Leedy 1989). Analytical surveys are concerned primarily with problems of estimation and with testing statistically based hypotheses (Leedy 1989).

Case studies are a type of both analytical and descriptive research in which data are gathered directly from individuals or groups in their natural environment for the purpose of studying interactions, attitudes or characteristics of individuals or groups. The observations lead to conclusions (Leedy 1989).

Sunderland (1990) describes case studies as not planned studies but retrospective reports of observations made on interesting individual patients. He suggests that they should not be seen as a means of objective evaluation of treatment, but as a source of clues on what clinical manoeuvres might be worth formal evaluation in future. The essence of the technique is that each subject studied, whether it be an individual, a group, or an institution, is treated as a unit on its own (McNeill 1985).

The case-study approach is particularly appropriate for individual researchers because it gives an opportunity for one aspect of a problem to be studied in some depth within a limited time scale (Bell 1987). Critics of the case-study approach draw attention to the fact that generalisation is not usually possible (Bell 1987).

There are two methods of observation according to Stacey (1969), that is, participant and non-participant. She

suggests that in the former observers join the group being studied as a member and attempt at the same time to be one of the observed as well as the observer. In the latter, observers are where the subjects are but are not one of them and may be observing through one way screen so that the subjects are unaware that they are being observed (Stacey 1969). However, McNeill (1985) suggests that true observation is when those being observed are unaware of the observations and that if the observer is visibly present, even though not participating, there can be suspicion that his presence is affecting what is happening (McNeill 1985).

4.1.2 **Descriptive Research.**

Descriptive research is most commonly used in occupational therapy research (Ethridge and McSweeney 1970). It shows conditions as they exist without being influenced by the investigator (Ethridge and McSweeney 1970). The techniques used include case studies, surveys, interviews and correlational analyses (Ethridge and McSweeney 1970).

Examples of descriptive occupational therapy research include Chiou and Burnett (1985), Hurd (1975), Parker and Thorslund (1991), Simpson (1987), Smith and Lincoln (1989), Soderback et al (1991), Strudwicke et al (1991),

Thompson and Coleman (1988) and Walker and Lincoln (1990).

Case study is a technique used both in analytical and descriptive research. It has been described earlier.

A survey is appropriate for data derived from simple observational situations, whether these are actually physically observed or observed through benefit of questionnaire or poll techniques (Leedy 1989). The descriptive survey method deals with a situation that demands the technique of observation as the principal means of collecting data (Leedy 1989).

The interview is a face to face data-gathering technique that can be conducted in two ways. A structured interview is closely allied to a questionnaire (Leedy 1989). The questions are carefully planned and are as accurately worded as the items in a questionnaire (Leedy 1989). The structured interview is favoured by researchers who attach importance to the objectivity of the research, and who wish to produce statistical data (McNeill 1985). An unstructured interview is more flexible and the form and order of the interview are left to the interviewer (McNeill 1985).

Correlational analysis is a statistical investigation of the relationship between one factor and one or more factors. Correlational research looks at surface relationships but does not necessarily probe for causal reasons underlying them (Leedy 1989).

Developmental study is an observational-descriptive type of research that usually stretches over a period of time and is also known as a longitudinal study (Leedy 1989).

4.1.3 **Experimental Research.**

The basic idea behind the experimental method is to attempt to account for the influence of a factor or factors conditioning a given situation (Leedy 1989). In most experimental and some survey studies a hypothesis is postulated, and the research is structured in such a way as to enable the hypothesis to be tested (Bell 1987).

Experimental research involves studying the effect of systematically varying conditions between two groups, e.g. with an experimental group and a control group (Ethridge and McSweeney 1970). The principle of experimental studies is that if two or more identical groups are selected, some of which (the experimental group) are given special treatment and the other (the control group) is

not, then any differences between the two groups at the end of the experimental period may be attributed to the difference in treatment. A causal relationship has been established (Bell 1987).

Examples of experimental occupational therapy research include Jongbloed and Morgan (1991), Krefting and Krefting (1991), Ostrow et al (1989), Pain and McLellan (1990), Sheikh et al (1978) and Smith et al (1982).

Single case experiments, according to Sunderland (1990), are investigations in which a series of different treatment approaches are tried with a single patient. These treatments are given in a sequence which is planned before the start of the experiment and the effectiveness of each is determined by comparing progress under each of the treatments. If it is sufficient to show that a treatment was effective in one particular patient then a single-case experiment is appropriate (Sunderland 1990). However, if the goal is to discover whether that treatment is the best approach to take with any patient of a particular type, than a randomized group trial is essential (Sunderland 1990).

Randomized controlled trials (RCT) are used to study the effect of a particular treatment on a population or

condition (Moffett 1991). The aim is to eliminate the possibility of reaching an erroneous or ambiguous conclusion, in particular attributing beneficial effects to a treatment which it does not in fact possess (Moffett 1991). They provide mathematical evidence either in support of or against one form of treatment compared with none or another form of treatment (Andrews 1991).

The RCT depends on several principles being observed (Andrews 1991):

- that the observer is unaware of which group is the treatment and which is the control group;
- that the patient is unaware of whether he is in the treatment or control group;
- that the outcome is measurable;
- that the measurement values have the same meaning for each subject;
- that any factor likely to affect the outcome will be equally distributed throughout the treatment and control groups.

The purpose of random allocation is to distribute prognostic factors evenly between the treatment and control groups (Gladman 1991). This allows eventual differences between the two groups to be attributed to the intervention under test.

4.2 STUDY DESIGN.

As this study is assessing the benefits of an intervention, the RCT technique was chosen. Randomized controlled trials are a productive way of assessing the effectiveness of treatment (Andrews 1991), whether the addition of a specific therapy programme has any benefit (Andrews 1991) or whether a particular treatment is the best approach to take with any patient of a particular type (Sunderland 1990). Gladman (1991) suggests that common and important problems in rehabilitation can only be answered authoritatively using randomized controlled trials.

4.3 ETHICAL APPROVAL.

Approval for this study was sought from the Ethics Committee of Division of Medicine, South Glamorgan Health Authority in February 1991 and was subsequently given.

4.4 RECRUITMENT OF PATIENTS.

Consecutive patients discharged from the two Stroke Units in South Glamorgan Health Authority over a ten month period were eligible for inclusion in this study. The recruitment from St David's Hospital Stroke Unit and Sully

Hospital Stroke Unit took place between 1st April 1991 and 31st January 1992. Following the move of St David's Hospital to the University Hospital of Wales (UHW) in September 1991, the recruitment continued from the stroke unit at UHW. A total of 110 patients were recruited.

4.5 ASSESSMENTS.

When comparing the effect of treatment on two or more groups of patients it is essential to ensure that the groups are as alike as possible so that a valid comparison of the effect of treatment can be made (Moffett 1991). In order to do this an assessment pack, for all patients admitted to the stroke units, was established (Appendix A). It comprised the Barthel ADL Index (Mahoney and Barthel 1965), the Wakefield Depression Scale, the Mini-Mental State Examination (Folstein et al 1975), and Albert's Perception Test (Albert 1973). These were administered to each of the patients at admission (within five days of admission) and at discharge. The Barthel ADL Index, and Albert's Test were administered by the occupational therapists on the units and the Mini-Mental State Examination and Wakefield Depression Scale were administered by the medical staff. Each of these assessments, and the reason for its selection, is described in detail earlier in the text.

Each stroke unit was visited by the researcher who informed the relevant staff about the assessment pack (Appendix A). A copy of each assessment, guidelines on its administration and scoring and reference articles on the assessments were given. Instructions were given regarding completing the summary sheet (top sheet of assessment pack) for each patient. This sheet contained details of the patient's name, address, date of onset of stroke, age, sex, marital status, number of days from onset of stroke to admission to stroke unit, past medical history, premorbid status (with reference to activities of daily living, mobility, mental state and continence), home circumstances prior to admission, statutory services received prior to admission, site of stroke, absence or presence of hemianopia, hospital acquired events, home circumstances on discharge, number of days in stroke unit, follow-up arrangements made on discharge and the total scores of each of the assessments administered on admission and discharge (Appendix A).

Each stroke unit has a ward receptionist who deals with the administration aspects of a ward. Both receptionists (from Sully Stroke Unit and St David's Stroke Unit) agreed to inform the research assistant (GG) at the Research Unit, Cardiff Royal Infirmary, of all discharges. Details of the patient's name and discharge address, General

Practitioner, date of discharge were given over the telephone to the research assistant (GG). This was followed up by the summary sheet of the assessment pack, which was sent to the research assistant (GG) in the addressed envelope provided, by internal mail, on the patient's discharge. (The ward receptionist in St David's Hospital transferred with the stroke unit to the University Hospital of Wales and continued to send the information as described.)

4.6 **RANDOMIZATION.**

On discharge from the stroke units information about each patient was sent to a research assistant (GG) at the Research Unit, Cardiff Royal Infirmary, in order for random allocation into control or intervention group to take place. This was conducted using random number tables in blocks of six. After allocation, information on those allocated to the intervention group was sent to the researcher. The allocation was prepared by a research assistant (GG) who was not going to be involved in the treatment and the patients were sequentially assigned to the groups according to the randomization as they entered the study. At the end of the randomization process 55 patients had been allocated to each of the control and intervention groups.

4.7 INFORMED CONSENT.

It was felt unnecessary to obtain informed consent from the control group as the intervention provided to the intervention group was in addition to treatment available to all patients discharged from South Glamorgan Stroke Units. Therefore the control group were still receiving the normal treatment available to all patients following discharge from a stroke unit.

All patients in the intervention group received a letter from their consultant, immediately after their discharge, informing them that an occupational therapist (SC) would be in contact with them in the next fortnight to make an appointment to visit (Appendix B). They were informed that the occupational therapist would visit within 1-2 weeks, and again later at 2, 4 and 6 months. The purpose of the visit was explained as a follow-up visit to see how patients were coping at home, to give advice and help with managing everyday activities and to help contact other services if appropriate. It was explained that the occupational therapist would answer any questions when she visited, or could be contacted by telephone and her number was provided.

Contact was made by telephone to all patients prior to each visit. The visit was arranged at a mutually agreeable time. If necessary the purpose of the visit was explained again. All patients (or their carers, or staff in residential homes on their behalf) consented to the visits.

At the time of discharge a letter was sent from the consultant to the patient's General Practitioner (Appendix B). This informed the General Practitioner that an occupational therapist (SC) would follow-up the patients to see if she could further improve their day-to-day functioning. A telephone number to contact her was given if they wished to discuss any stroke related problems with her.

4.8 INTERVENTIONS.

The intervention group were reviewed regularly by an occupational therapist, at two weeks, two months, four months and six months following discharge. Each patient received a letter immediately post-discharge to inform them that the occupational therapist would be contacting them. Each subsequent visit was arranged by telephone.

The interventions involved:

- formal review by interview and observation of all patients, at intervals of two weeks, two months, four months and six months post discharge, of functional levels of independence, at which a problem list was formulated and treatment plans were drawn up;
- informal contact as appropriate at other times;
- treatment programme planning to improve/maintain levels of independence, using such activities as washing, feeding, bathing, dressing, and grooming practice; kitchen work including preparation of hot drink, snack (ie cheese on toast) and main meal; practice of transfers ie sitting from standing, standing from sitting, from chair to chair, from bed to chair;
- maintaining up-to-date information of resources available to stroke patients including information and contacts of local Stroke Support Groups, Carers Association, local Stroke Association Information Centre, Volunteer Stroke Scheme, Day Centres, Day Break, Crossroads, and the Rosemarie Lewis Stroke Interest Group;
- referring to services as appropriate including General Practitioner, Community Occupational Therapist, Community Physiotherapist, Community Speech Therapist, Community Dietitian, Social Worker, Voluntary Agencies, Day Hospital, Social Services and Continence Advisor;

- liaison with other sources of intervention ie Day Hospital Occupational Therapists, Social Services and Community Therapists;
- recording results of all assessments;
- documenting all interventions including referrals to and liaisons with other services.

4.9 FINAL OUTCOME MEASURE.

In order to assess the benefits of the intervention it was necessary to compare the patients' levels of functional competence in the control and intervention groups one year post-stroke. This assessment should have been carried out either by an independent assessor (blind to the allocated group) or by post. No independent assessor was available; therefore, it was conducted by post.

A year post stroke each patient was sent a questionnaire with a covering letter, a stamped addressed envelope to return the questionnaire and a sealed envelope addressed to their carer (Appendix C). The areas measured included:

- activities of daily living;
- extended activities of daily living;
- mood;
- quality of life;
- patient satisfaction;

- use of services at discharge and a year post stroke;
- carers' quality of life;
- carers' stress.

The following assessments were used to measure the above:
- Barthel Activity of Daily Living Index;
- Nottingham Extended ADL Index;
- Geriatric Depression Scale;
- Pearlman's Quality of Life Scale;
- Green's Scale of Carers Strain.

Each of these scales and the reason for their selection has been discussed earlier (Chapter 3).

The envelope for the carer contained a letter to the carer, a questionnaire and a stamped addressed envelop to return the questionnaire (Appendix C). The letter explained that the purpose of the questionnaire was to highlight the areas in a carer's life that are most affected when someone close to them has had a stroke. It was highlighted that their answers would assist in planning and developing services in the future. They were thanked for their help and cooperation.

If the completed questionnaires were not returned by two weeks after posting, a second copy was sent out. Efforts were made by contacting patients' General Practitioner to

verify addresses if the second mailing was not returned. One patient in the control group did not return the questionnaire and it was established that the patient had moved and no forwarding address was known.

4.10 DATA ANALYSIS.

The data analysis for this study was conducted using SPSS/PC+, a statistical package for social sciences. For all tests used a significance value of less than p=0.05 was considered to be statistically significant. Where appropriate all test were two tailed. The following tests were used to analyse the data:

- chi-square test for association (X^2=) was used to compare categorical variables (for example, sex, marital status);
- Fisher's Exact Test was used when the frequency of observations were too small for a chi-square test analysis;
- Mann-Whitney test corrected for ties (z=) was used for a non-normal distribution (for example, days on stroke unit);
- T-test (t=) was used for interval variables with a normal distribution (for example, age).

4.11 SUMMARY.

Occupational therapists are beginning to develop a greater appreciation of research and knowledge development. Although both quantitative and qualitative procedures are used by occupational therapists, experimental research is quite rare in occupational therapy.

A randomized controlled trial was conducted, with the intervention group receiving occupational therapy at regular intervals post discharge. A year post stroke a questionnaire assessing levels of independence in activities of daily living, social functioning, mood, quality of life, use of services and carer's stress was sent to all patients. The analysis of the data was conducted by a statistical package for social sciences.

The results are described in the next chapter.

CHAPTER 5.

RESULTS.

5. RESULTS.

5.1 BASELINE INFORMATION.

The purpose of the baseline information section is to describe patients who are admitted to stroke units in South Glamorgan. It also is to establish that the randomization procedure resulted in comparable patients in each of the control and intervention groups.

The number of patients recruited to the study was 110, 55 in each of the control and intervention group. Calculating the sample size for this study was difficult because no previous studies were available for guidelines of numbers to include or expected outcome (that is, none that had compared occupational therapy with no occupational therapy) and limitations of time. The time period for recruiting the patients was extended for as long as possible in order to recruit as many patients as possible.

When comparing the control and intervention groups there were no statistically significant differences in age, number who had a previous stroke or side of stroke (Table 5.1). Despite random allocation, significant differences were noted between the control group and the intervention

group for sex (males 26(47%) vs 15(27%) respectively, chi-square value (X^2)=4.7,df=1,p=0.03).

There were no statistically significant differences between the two groups in terms of marital status, home circumstances pre and post stroke or whether the patients were discharged to their previous home (Table 5.2).

Table 5.1 Clinical features of the two groups of stroke patients.

	Control (n=55)	Intervention (n=55)		
AGE (years)				
Mean	75.8	75.1	t=0.44	p=0.65
Range	54-94	41-96		
SEX				
Male	26(47%)	15(27%)	X^2=4.7 df=1	p=0.03
Female	29(53%)	40(73%)		
PREVIOUS STROKE *				
Yes	9(17%)	12(23%)	X^2=0.6 df=1	p=0.43
No	45(83%)	41(77%)		
SIDE OF STROKE *				
Right Hemisphere	26(48%)	26(49%)	X^2=0.1 df=1	p=0.90
Left Hemisphere	25(46%)	25(47%)		
Vertebro-basilar	3(6%)	2(4%)		

* information was missing for 1 patient in the control group and 2 in the intervention group.

Table 5.2 Social circumstances pre-admission and post-discharge of the stroke patients in the two groups.

	Control (n=55)	Intervention (n=55)			
MARITAL STATUS *					
Single/Div/Wid	29(53%)	36(67%)	X^2=2.1	df=1	p=0.13
Married	26(47%)	18(33%)			
LIVES PRE ADMISSION *					
Alone	16(29%)	24(44%)	X^2=3.3	df=2	p=0.18
With other	35(64%)	25(46%)			
Shel/Res/Nurse Home	4(7%)	5(10%)			
LIVES POST ADMISSION					
Alone	5(9%)	8(14%)	X^2=1.2	df=2	p=0.52
With other	23(42%)	25(46%)			
Shel/Res/Nurse Home	27(49%)	22(40%)			
DISCHARGED TO					
Previous home	29(53%)	33(60%)	X^2=0.5	df=1	p=0.44
New accommodation	26(47%)	22(40%)			

* this information was missing for 1 patient in the intervention group.

Also no statistically significant difference was noted between the control and intervention in which hospital stroke unit the patients were admitted to (Table 5.3). However, more patients in both groups were recruited from the St David's/UHW stroke unit which has more beds than the Sully Hospital Stroke Unit (32 vs 18). The median

length of time in days from onset of stroke to transfer to the stroke unit or the number of days on the stroke unit were not significantly different between the two groups (Table 5.3).

There were no statistically significant differences in the reported pre admission levels of function in activities of daily living, mobility, mental state and continence between the two groups (Table 5.4). This information was collected by the medical and paramedical staff on the stroke units, from information given by the patient and/or relatives and not by using standardised assessments.

Table 5.3 The details of stroke unit admission of the two groups.

	Control (n=55)	Intervention (n=55)			
HOSPITAL					
St David's/UHW	30(55%)	31(56%)	X^2=0.0	df=1	p=0.84
Sully	25(45%)	24(44%)			
DAYS FROM ONSET TO STROKE UNIT					
Median	10	11.5	z=-1.47		p=0.13
Range	1-52	2-88			
DAYS ON STROKE UNIT					
Median	50	50	z=-0.61		p=0.53
Range	7-169	5-229			

Table 5.4 The details of pre-admission levels of function of patients in the two groups.

	Control (n=55)	Intervention (n=55)	
ADL STATUS PRE ADMISSION *			
Independent	41(75%)	46(84%)	X^2=1.9 df=2 p=0.37
Needs help	8(15%)	5(9%)	
Dependent	6(11%)	3(6%)	
MOBILITY PRE ADMISSION *			
Walks unaided	42(76%)	49(91%)	X^2=4.0 df=2 p=0.12
Walks with help	8(15%)	3(5%)	
Immobile	5(9%)	2(4%)	
MENTAL STATE PRE ADMISSION **			
Normal	46(87%)	51(95%)	Fisher's Test p=0.20
Confused	7(13%)	3(5%)	
CONTINENCE PRE ADMISSION ***			
Continent	45(87%)	51(94%)	X^2=2.3 df=2 p=0.31
Occasional incontinent	3(5%)	2(4%)	
Incon/catheter in situ	4(8%)	1(2%)	

* information missing for 1 patient in the intervention group.
** information missing for 2 patients in the control group and 1 in the intervention group.
***information missing for 3 patients in the control group and 1 in the intervention group.

Home Help was the most commonly used service by the patients prior to admission. There were no statistically significant differences between the two groups for use of Home Help, Meals on Wheels, Community Nurse and Day Hospital prior to admission (Table 5.5).

On discharge there were a number of options available for continued rehabilitation, if appropriate. Only a small number of patients were referred to outpatient occupational therapy, physiotherapy and speech therapy (Table 5.6) and there were no statistically significant differences between the two groups for these referrals. Day hospital is another option for further rehabilitation and there was a significant difference between the two groups as 43(78%) of the intervention group were referred compared with 28(55%) of the control group ($X^2=6.4, df=1, p=0.01$). As this difference may have influenced outcome in the two groups, it was taken into consideration in subsequent comparisons between the groups.

Table 5.5 The details of the number of patients in each group using Home Help, Meals on Wheels, Community Nurse and Day Hospital services prior to admission.

	Control (n=55)	Intervention (n=55)	
Home Help *	6(11%)	11(21%)	X^2=1.9 df=1 p=0.16
Meals on Wheels *	3(5%)	1(2%)	Fisher's Test p=0.61
Community Nurse *	1(2%)	1(2%)	Fisher's Test p=1.00
Day Hospital **	3(5%)	2(4%)	Fisher's Test p=1.00

* information missing for 2 patients in the intervention group.
** information missing for 1 patients in the control group and 2 in the intervention group.

Table 5.6 The number of patients in each group who were referred to Day Hospital, outpatient occupational therapy, outpatient physiotherapy or outpatient speech therapy following discharge from the stroke unit.

	Control (n=55)	Intervention (n=55)	
Day hospital	28(55%)	43(78%)	X^2=6.4 df=1 p=0.01
Occupational Therapy	1(2%)	3(6%)	Fisher's Test p=0.61
Physiotherapy	3(6%)	4(7%)	Fisher's Test p=1.00
Speech Therapy	4(8%)	2(4%)	Fisher's Test p=0.42

Information missing for 4 patients in the control group.

Comparison of the results of the Barthel ADL Index, Mini Mental State Examination, Wakefield Depression Scale, and Albert's Perception Test on admission for both groups was unsatisfactory as so many of the results were missing (Table 5.7). This is despite agreements from the various medical and paramedical staff (and frequent reminders) that these assessments would be carried out on all the patients within five days of admission. Of those for whom results were available, there was no significant difference in the Barthel ADL Index between the two groups ($z=-0.92, p=0.35$), although a larger percentage of the control group had a score of more than 12 (25% vs 14%).

There were no statistically significant differences between the groups for the Mini Mental State Examination scores, the Wakefield Depression Scale scores or the Albert's Perception Test on admission.

Table 5.7 Results of the Barthel ADL Index, Mini Mental State Examination, Wakefield Depression Scale, and Albert's Perception Test on admission for both groups.

	Control (n=55)	Intervention (n=55)		
BARTHEL ADL INDEX				
Median	6	8	z=-0.92	p=0.35
Interquartile Range	3-12	4-10		
No.(%) Score </=12	40(75%)	43(86%)		
No.(%) Score >12	13(25%)	7(14%)		
Missing	2	5		
MINI MENTAL STATE EXAMINATION				
Median	18.5	23	z=-1.75	p=0.07
Interquartile Range	12-24	17-26		
No.(%) Score </=23	27(67%)	25(58%)		
No.(%) Score >23	13(33%)	18(42%)		
Missing	15	12		
WAKEFIELD DEPRESSION SCALE				
Median	14.5	11	z=-0.52	p=0.59
Interquartile Range	7-19	7-18		
No. Score </=14(No)	16(50%)	25(63%)		
No. Score 15-18(prob)	6(19%)	5(12%)		
No. Score >/=19(yes)	10(31%)	10(25%)		
Missing	23	15		
ALBERT'S PERCEPTION TEST				
Inattention	13(36%)	13(31%)	X^2=0.2 df=1	p=0.62
No inattention	23(64%)	29(69%)		
Missing	19	13		

The problem of missing data was even more evident when comparing the results of the Barthel ADL Index, Mini Mental State Examination, Wakefield Depression Scale, and Albert's Perception Test on discharge for both groups (Table 5.8). The results of the Mini Mental State Examination were missing for 54 patients, the results of the Wakefield Depression Scale were missing for 61 patients and the results of the Albert's Perception Test were missing for 51 patients.

For those for whom the data was available there were no statistically significant differences between the groups at discharge in the Barthel ADL Index, Mini Mental State Examination, Wakefield Depression Scale, and Albert's Perception Test.

Table 5.8 Results of the Barthel ADL Index, Mini Mental State Examination, Wakefield Depression Scale, and Albert's Perception Test on discharge for both groups.

	Control (n=55)	Intervention (n=55)		
BARTHEL ADL INDEX				
Median	14	15	z=-0.82	p=0.40
Interquartile Range	6-18	10-18		
No.(%) Score </=12	23(47%)	18(38%)		
No.(%) Score >12	26(53%)	30(62%)		
Missing	6	7		
MINI MENTAL STATE EXAMINATION				
Median	24	25	z=-0.92	p=0.35
Interquartile Range	18-27	22-28		
No.(%) Score </=23	11(48%)	14(42%)		
No.(%) Score >23	12(52%)	19(58%)		
Missing	32	22		
WAKEFIELD DEPRESSION SCALE				
Median	10	12	z=-1.04	p=0.29
Interquartile Range	0-21	1-24		
No. Score </=14(No)	15(72%)	19(68%)		
No. Score 15-18(prob)	4(19%)	4(14%)		
No. Score >/=19(yes)	2(9%)	5(18%)		
Missing	34	22		
ALBERT'S PERCEPTION TEST				
Inattention	3(13%)	3(9%)	Fisher's Test	p=0.67
No inattention	21(87%)	32(91%)		
Missing	31	20		

5.2 INTERVENTIONS.

Each patient in the intervention group was reviewed by the researcher at two weeks, two months, four months and six months post discharge. During these visits the patients' levels of independence in activities of daily living were established by observation and interview. Together with the patients (and carer if appropriate), a problem list and treatment plan was agreed.

This section of the results chapter describes the different interventions carried out, such as teaching new skills, enabling patients to use equipment supplied by other agencies, for example, social services, giving information to the patient and carer and referring to or liaising with other agencies. It also gives information on the length of time spent in direct or indirect contact with the patients. Indirect contact includes such activities as contacting various agencies to discuss the patient and completing the administration papers related to the patient.

At two weeks post discharge 54 of the 55 patients in the intervention group were visited. One patient was not visited at the request of the staff in the residential home where she lived because of an infectious condition. One patient was visited twice because the carer requested

a second visit shortly after the first. By two months post discharge two patients had deceased, the remaining 53 patients were visited once. At four months post discharge a further 3 patients had deceased. One patient was visited twice and the remaining 49 once. Two more patients had died by six months post discharge. One patient was visited twice and the remaining 47 once.

The median time spent with each patient for the first two visits was 30 minutes. This decreased to 25 minutes for the visits at four and six months (Table 5.9). The median time spent in indirect contact (making telephone calls, discussing with others) for each patient was considerably less (Table 5.10). Following the first visit the median time was 10 minutes, 5 minutes after the visits at two and four months and 7.5 minutes after the last visit.

The median mileage for each of the four visits was the same, that is, twelve miles (Table 5.11). However, the range was 0-28 miles at the first visit increasing to 92 miles for the second and subsequent visits. This was due to the fact that one patient moved out of the area, firstly to a residential home and then to her brother's home between the visits.

Table 5.9 Time (minutes) per visit spent in direct contact with the patients during the four visits.

	Two Weeks	Two Months	Four Months	Six Months
Median	30	30	25	25
Range	5-60	5-60	5-75	5-60

Table 5.10 Time (minutes) spent in indirect contact with the patients as a result of the four visits.

	Two Weeks	Two Months	Four Months	Six Months
Median	10	5	5	7.5
Range	5-45	5-20	5-35	5-75

Table 5.11 Distance (miles) driven in order to carry out the four visits.

	Two Weeks	Two Months	Four Months	Six Months
Median	12	12	12	12
Range	2-28	2-92	2-92	2-90

Table 5.12 The levels of function in activities of daily living as measured by the Barthel ADL Index, of the patients at each of the four visits post discharge.

	Two Weeks	Two Months	Four Months	Six Months
Median	14	14	16	16
Interquartile Range	10-17	10-17	11-18	12-18
No. Score </=12	22(41%)	24(45%)	16(32%)	12(25%)
No. Score >12	32(59%)	29(55%)	34(68%)	36(75%)
No. Deceased	-	2	5	7

During each visit the patients' levels of function in activities of daily living were assessed using the Barthel Activities of Daily Living Index. The median score at the first and second visit was 14. This increased to 16 at the third and last visit (Table 5.12). Fifty-nine percent of patients had a score of more than 12 at the first visit. This increased to 75% at the last visit and was 55% and 68% at the second and third visits respectively.

The researcher liaised with or referred to a number of statutory and voluntary agencies (Table 5.14). All this was done either by telephone or by personal visit to the agency by the researcher. Examples of the liaison included contacting the occupational therapist in social services about promised equipment that had not yet arrived and informing the day hospital occupational therapist of problems that patients had in activities of daily living

in their home environment. Although the researcher did not make any referrals to day hospital almost half of the liaisons 41 (45%) were with the day hospital staff. Other liaisons were with clinical psychologist, community memory project, community occupational therapist, community physiotherapist, district nurse, general practitioner, disabled resettlement officer, stroke support groups and social workers.

The researcher made a total of 92 referrals to other agencies (Table 5.13). Sixty (65%) of these referrals were made following the two week visit. Referrals were made to the stroke support groups, social services, disabled resettlement officer, and voluntary agencies such as Women's Royal Voluntary Service, Day Break and the Volunteer Stroke Scheme.

Table 5.13 The number of referrals and liaisons made by the researcher in the various time periods.

	Two Weeks	Two Months	Four Months	Six Months	Total
Referrals	60	21	9	6	92
Liaisons	30	27	24	10	91

Table 5.14 A list of the different agencies that the researcher liaised with or referred to during study.

	No. of referrals	No. of liaisons
Clinical Psychologist	1(1%)	1(1%)
Community Memory Project	1(1%)	1(1%)
Community Occupational Therapist	1(1%)	3(3%)
Community Physiotherapist	-	2(2%)
Crossroads	1(1%)	-
Daybreak	4(4%)	-
Day Centre	2(2%)	-
Day Hospital	-	41(45%)
Disablement Resettlement Officer	2(2%)	2(2%)
District Nurse	1(1%)	1(1%)
General Practitioner	2(2%)	1(1%)
Home Care	3(3%)	-
Orange Badge Scheme	9(10%)	3(3%)
Outpatient Physiotherapy	-	2(2%)
Social Services Occupational Therapist	5(5%)	8(9%)
Stroke Support Groups	44(48%)	11(12%)
Social Worker	6(7%)	11(12%)
Social Worker for the Blind	-	1(1%)
Volunteer Stroke Scheme	9(10%)	3(3%)
Women's Royal Voluntary Service	2(2%)	2(2%)
Total	92(100%)	91(100%)

5.3 COMPARISON OF THE TWO GROUPS AT ONE YEAR POST STROKE.

At one year post stroke efforts were made via the GP to confirm each patient's address. Eleven of the control and nine of the intervention group had deceased. The remaining 90 patients were sent a questionnaire. If a completed questionnaire was not returned by two weeks a second questionnaire was sent. One patient in the control group did not return the questionnaire. It was established from a neighbour that the patient had moved out of the area and that a forwarding address was not available. This section of the results chapter reports data from the 89 questionnaires returned. Seven (17%) of the control group and eight (17%) of the intervention group completed the questionnaire themselves (X^2=0.00,df=1,p=0.96), while the remainder had assistance from relatives or carers.

The first table (Table 5.15) describes the home circumstances at discharge of all the patients (including those who later deceased) and describes the home circumstances of the survivors at one year post stroke. As some categories were small it was decided to combine them in order to carry out statistical analysis. Table 5.16 uses the combined categories to describe the home circumstances at discharge of all the patients and the home circumstances of the survivors at one year post

stroke. The new categories were 'living alone', 'with others' which included those with a spouse, with a friend or relative, with son or daughter or in sheltered accommodation and 'institutional care' which included those in residential or nursing homes. There was no statistically significant difference in home circumstances at discharge between the two groups (X^2=0.2,df=2,p=0.29).

At one year post stroke, 11 of the patients in the control group and 9 in the intervention group had died. Of the remaining patients, there was no statistically significant difference between the two groups in home circumstances (X^2=1.4,df=3,p=0.68). Although at one year the total number of patients in the two groups in institutional care was similar (18 vs 16), more control patients were in nursing homes whereas in the intervention group the patients were equally distributed between residential and nursing homes.

There are no significant differences between the control and intervention groups a year post stroke in individual items of activities of daily living as measured by the Barthel ADL Index or for total scores (Table 5.17). The percentage of patients in the control group with a score of more than 12 was 49% compared with 52% in the intervention group.

Table 5.15 Home circumstances of patients in the two groups at discharge and at one year post stroke.

	Control (n=55)	Intervention (n=55)
HOME CIRCUMSTANCES ON DISCHARGE		
Alone	5(9%)	8(14%)
With spouse	18(33%)	15(27%)
With friend or relative	2(4%)	3(6%)
With son or daughter	5(9%)	6(11%)
Sheltered accommodation	2(4%)	1(2%)
Residential home	6(11%)	12(22%)
Nursing home	17(31%)	10(18%)
HOME CIRCUMSTANCES ONE YEAR POST STROKE *		
Alone	5(12%)	9(20%)
With spouse	13(30%)	12(26%)
With friend or relative	2(5%)	3(7%)
With son or daughter	2(5%)	4(9%)
Sheltered accommodation	3(7%)	2(4%)
Residential home	2(5%)	8(17%)
Nursing home	16(37%)	8(17%)
Deceased	11	9

* information was missing for 1 patient in the control group.

Table 5.16 Details of where patients live and with whom on discharge and one year post stroke.

	Control (n=55)	Intervention (n=55)			
LIVES WITH AT DISCHARGE					
Alone	5(9%)	8(15%)	X^2=0.2	df=2	p=0.29
With others	27(49%)	25(45%)			
Res/Nurse Home	23(42%)	22(40%)			
LIVES WITH ONE YEAR POST STROKE					
Alone	5(12%)	9(19%)	X^2=1.4	df=3	p=0.68
With others	20(47%)	21(45%)			
Res/Nurse Home	18(41%)	16(30%)			
Deceased	11	9			

Table 5.17 The number of patients independent in activities of daily living, as measured by the Barthel ADL Index and total Barthel scores of patients who returned the questionnaire in the two groups one year post stroke.

	Control (n=43)	Intervention (n=46)			
BATHING	3(7%)	6(13%)	Fisher's Test		p=0.48
STAIRS	8(19%)	9(20%)	X^2=0.9	df=2	p=0.63
DRESSING	8(19%)	13(28%)	X^2=4.0	df=2	p=0.13
INDOOR WALKING	21(49%)	23(50%)	X^2=1.1	df=3	p=0.76
TRANSFERS	19(44%)	27(59%)	X^2=5.4	df=3	p=0.13
FEEDING	15(35%)	17(37%)	X^2=1.1	df=2	p=0.57
USE TOILET	23(53%)	25(54%)	X^2=1.9	df=2	p=0.37
GROOMING	22(51%)	29(63%)	X^2=1.2	df=1	p=0.25
BLADDER Continent	23(53%)	28(60%)	X^2=0.8	df=2	p=0.64
BOWEL Continent	24(56%)	27(59%)	X^2=0.0	df=2	p=0.96

Table 5.17 Contd. **The number of patients independent in activities of daily living, as measured by the Barthel ADL Index and total Barthel scores of patients who returned the questionnaire in the two groups one year post stroke.**

	Control (n=43)	Intervention (n=46)		
BARTHEL SCORE				
Median	12	13	z=-0.74	p=0.45
Interquartile Range	6-15	10-15		
No.(%) Score </=12	22(51%)	22(48%)		
No.(%) Score >12	21(49%)	24(52%)		

Table 5.18 shows the number of patients independent in extended activities of daily living, as measured by the Nottingham Extended ADL Scale, in the two groups a year post stroke. More patients in the intervention group are independent than those in the control group in feeding themselves (56% vs 76%, $X^2=4.0, df=1, p=0.04$) and using the telephone (33% vs 65%, $X^2=9.4, df=1, p=0.002$). There was no significant difference between the groups for any of the other items of the Nottingham Extended ADL Scale.

Table 5.18 The number of patients independent in extended activities of daily living, as measured by the Nottingham Extended ADL Scale, of patients who returned the questionnaire in the two groups one year post stroke.

	Control (n=43)	Intervention (n=46)			
OUTDOOR WALKING	16(37%)	15(33%)	X^2=0.2	df=1	p=0.64
CLIMB STAIRS	13(30%)	12(26%)	X^2=0.1	df=1	p=0.66
IN AND OUT OF CAR	14(33%)	10(22%)	X^2=1.3	df=1	p=0.25
WALK ON UNEVEN GROUND	13(30%)	10(22%)	X^2=0.8	df=1	p=0.36
CROSS ROADS	9(21%)	6(13%)	X^2=0.9	df=1	p=0.32
USE ON PUBLIC TRANSPORT	4(9%)	4(8%)	Fisher's Test		p=1.00
FEED YOURSELF	24(56%)	35(76%)	X^2=4.0	df=1	p=0.04
MAKE HOT DRINK	11(26%)	18(39%)	X^2=1.8	df=1	p=0.17
CARRY DRINK	12(28%)	12(26%)	X^2=0.0	df=1	p=0.84
WASHING UP	11(26%)	14(30%)	X^2=0.2	df=1	p=0.61
MAKE HOT SNACK	9(21%)	15(33%)	X^2=1.5	df=1	p=0.21
MANAGE MONEY *	12(28%)	12(27%)	X^2=0.0	df=1	p=0.89
WASH SMALL ITEMS	6(14%)	11(24%)	X^2=1.4	df=1	p=0.23
DO HOUSEWORK	5(12%)	4(9%)	Fisher's Test		p=0.73
SHOPPING	6(14%)	3(6%)	Fisher's Test		p=0.30
FULL CLOTHES WASH	5(12%)	1(2%)	Fisher's Test		p=0.10
READ NEWSPAPERS	30(70%)	34(74%)	X^2=0.1	df=1	p=0.66
USE TELEPHONE	14(33%)	30(65%)	X^2=9.4	df=1	p=0.002
WRITE LETTERS	10(23%)	12(26%)	X^2=0.0	df=1	p=0.75
GO OUT SOCIALLY	1(2%)	3(6%)	Fisher's test		p=0.61
MANAGE GARDEN	3(7%)	1(2%)	Fisher's Test		p=0.34
DRIVE A CAR	1(2%)	1(2%)	Fisher's Test		p=1.00

* information missing for 1 intervention patient.

Table 5.19 Details of subtotal and total Nottingham Extended ADL Scale scores of patients who returned the questionnaire in the two groups one year post stroke.

	Control (n=43)	Intervention (n=46)		
Mobility subtotal Extended ADL				
Median	0	0	z=-0.27	p=0.78
Range	0-6	0-6		
Kitchen subtotal Extended ADL				
Median	1	1	z=-1.49	p=0.13
Range	0-5	0-5		
Domestic subtotal Extended ADL *				
Median	0	0	z=-0.36	p=0.71
Range	0-5	0-5		
Leisure subtotal Extended ADL				
Median	1	2	z=-1.81	p=0.06
Range	0-5	0-5		
EXTENDED ACTIVITIES OF DAILY LIVING SCALE *				
Median	2	3	z=-1.11	p=0.26
Range	0-21	0-20		

* information missing for 1 intervention patient.

There are no significant differences between the two groups in the subtotal and total scores of the Nottingham Extended ADL Scale (Table 5.19). However, the authors of the Nottingham Extended ADL Scale suggest that the scale is most suitable for use with those living in the community (Nouri and Lincoln 1987). As a consequence the data has been further analysed in relation to those who were living alone, with others or in sheltered accommodation a year post stroke (Table 5.20).

As with the total group, fewer patients in the control group were independent than those in the intervention group in feeding themselves (15(50%) vs 25(83%), X^2=3.7,df=1, p=0.05) and using the telephone (14(52%) vs 23(77%) X^2=3.6,df=1,p=0.05). However more patients in the control group are independent than those in the intervention group in terms of getting in and out of a car (14(56%) vs 9(30%), X^2=3.7,df=1,p=0.05) and doing a full clothes wash (5(20%) vs 1(3%), Fisher's Exact Test p=0.04). There was no significant difference between the groups for any of the other extended ADL items (Table 5.20) or for the total or subtotal scores (Table 5.21).

Table 5.20 The number of patients independent in extended activities of daily living of patients who live either alone, with others or in sheltered accommodation and who returned the questionnaire in the two groups one year post stroke.

	Control (n=25)	Intervention (n=30)			
OUTDOOR WALKING	16(64%)	13(43%)	X^2=2.3	df=1	p=0.12
CLIMB STAIRS	13(52%)	12(40%)	X^2=0.7	df=1	p=0.37
IN AND OUT OF CAR	14(56%)	9(30%)	X^2=3.7	df=1	p=0.05
WALK ON UNEVEN GROUND	13(52%)	9(30%)	X^2=2.7	df=1	p=0.09
CROSS ROADS	9(36%)	6(20%)	X^2=1.7	df=1	p=0.18
USE PUBLIC TRANSPORT	4(16%)	4(13%)	Fisher's Test		p=0.78
FEED YOURSELF	15(50%)	25(83%)	X^2=3.7	df=1	p=0.05
MAKE HOT DRINK	11(44%)	18(60%)	X^2=1.4	df=1	p=0.23
CARRY DRINK	12(48%)	12(40%)	X^2=0.3	df=1	p=0.55
WASHING UP	11(44%)	14(47%)	X^2=0.0	df=1	p=0.84
MAKE HOT SNACK	9(36%)	14(47%)	X^2=0.6	df=1	p=0.42
MANAGE MONEY *	12(48%)	10(34%)	X^2=1.0	df=1	p=0.31
WASH SMALL ITEMS	6(24%)	10(33%)	X^2=0.5	df=1	p=0.44
DO HOUSEWORK	5(20%)	4(13%)	Fisher's Test		p=0.50
SHOPPING	6(24%)	3(10%)	Fisher's Test		p=0.16
FULL CLOTHES WASH	5(20%)	1(3%)	Fisher's Test		p=0.04
READ NEWSPAPERS	19(76%)	23(77%)	X^2=0.0	df=1	p=0.95
USE TELEPHONE	14(52%)	23(77%)	X^2=3.6	df=1	p=0.05
WRITE LETTERS	7(28%)	8(27%)	X^2=0.0	df=1	p=0.91
GO OUT SOCIALLY	1(4%)	3(10%)	Fisher's Test		p=0.39
MANAGE GARDEN	3(12%)	1(3%)	Fisher's Test		p=0.21
DRIVE A CAR	1(4%)	1(3%)	Fisher's Test		p=0.89

* information missing for 1 patient in the intervention group.

Table 5.21 Details of subtotal and total Nottingham Extended ADL Scale scores of patients who live either alone, with others or in sheltered accommodation who returned the questionnaire in the two groups one year post stroke.

	Control (n=25)	Intervention (n=30)		
Mobility subtotal of Extended ADL Scale				
Median	0	0	z=-1.53	p=0.12
Range	0-6	0-6		
Kitchen subtotal of Extended ADL Scale				
Median	1	1	z=-0.74	p=0.45
Range	0-5	0-5		
Domestic subtotal of Extended ADL Scale*				
Median	0	0	z=-0.56	p=0.57
Range	0-5	0-5		
Leisure subtotal of Extended ADL Scale				
Median	1	2	z=-0.71	p=0.47
Range	0-5	0-5		
EXTENDED ADL SCALE*				
Median	2	3	z=-0.20	p=0.84
Range	0-21	0-20		

* information is missing for 1 patient in the intervention group.

There was no statistically significant difference between the two groups of patients in their scores for the Short Geriatric Depression Scale (Table 5.22). In both groups, the majority of patients (24(68%) control and 32(80%) intervention) had a score of 6 or more which is indicative of depression of various degrees.

Table 5.22 The results of the Short Geriatric Depression Scale for both groups.

	Control (n=43)	Intervention (n=46)	
Median	8	7	z=-0.66 p=0.50
Range	2-12	4-13	
No.(%) Score </=5(normal)	11(32%)	8(20%)	
No.(%) Score 6-10(mild dep)	19(54%)	22(54%)	
No.(%) Score 11-15(mod/sevr)	5(14%)	11(26%)	

Information was missing for 8 patients in the control group and 5 in the intervention group.

Two patients in the control and two in the intervention group did not indicate how satisfied they were with life (Table 5.23). It was not possible to statistically analyse the patients' response due to the small numbers in some categories. Consequently categories were combined and further analysis carried out (Table 5.24).

There was no statistically significant difference between the two groups when the life satisfaction answers were combined (X^2=0.05,df=1,p=0.80) (Table 5.24). 'Good' included 'about as good as it can be', 'good enough' and 'fair' combined, while 'poor' included 'not so good', 'not good at all' and 'terrible' combined.

Table 5.23 Patients' indication of how satisfied they feel with life.

	Control (n=43)	Intervention (n=46)
LIFE SATISFACTION		
About as good as it can be	15(37%)	14(32%)
Good enough	5(12%)	4(9%)
Fair	6(17%)	11(25%)
Not so good	12(29%)	14(32%)
Not good at all	2(5%)	1(2%)
Terrible	1(2%)	-

Information was missing for 2 patients in both the control and intervention groups.

Table 5.24 Patients' indication of whether they feel their life satisfaction was good or poor.

	Control (n=43)	Intervention (n=46)	
Good	26(63%)	29(66%)	X^2=0.05 df=1 p=0.80
Poor	15(37%)	15(34%)	

Information was missing for 2 patients in both the control and intervention groups.

The carers were invited to answer whether they felt the patients' life satisfaction was good or poor (Table 5.25). The carer was either the person who was living with the patient, a carer from a statutory service, for example, Home Carer or a member of staff from a nursing or residential home. There was no statistically significant difference between the two groups for carers' perception of patients' life satisfaction. Both carers and patients had a similar perception of life satisfaction as two thirds of the patients and two thirds of the carers thought that the patients' life satisfaction was good (Table 5.24 and Table 5.25)

Table 5.25 Carers' indication of whether they feel the patients' life satisfaction was good or poor.

	Control (n=43)	Intervention (n=46)			
Good	24(63%)	26(62%)	X^2=0.01	df=1	p=0.90
Poor	14(37%)	16(38%)			

Information was missing for 5 patients in the control and 4 patients in the intervention groups.

Day hospital and outpatient therapy are facilities available for patients after discharge from a stroke unit if it is thought that they would benefit from further rehabilitation. There was a statistically significant difference between those patients in the control group and those in the intervention group who attended day hospital following discharge (18(43%) vs 35(76%) X^2=10.1,df=1, p=0.001). Information was missing for one patient in the control group. Of those patients attending day hospital at discharge, four (22%) in the control group were still attending one year later as were 14(40%) of the intervention group. This difference was not statistically significant (X^2=1.67,df=1,p=0.19).

There was a statistically significant difference in the number of patients in the control and intervention groups attending outpatient occupational therapy on discharge

(3(7%) vs 14(32%) X^2=8.24,df=1,p=0.004) (Table 5.26). No statistically significant difference was present for attending outpatient physiotherapy or outpatient speech therapy on discharge (Table 5.26).

Only a small number of patients were attending outpatient therapy one year post stroke and there was no statistically significant difference between the control and intervention groups for this (Table 5.27).

As expected there was a statistically significant difference between the control and intervention group for those receiving occupational therapy at home (1(2%) vs 21(49%) X^2=22.4,df=1,p=0.004) (Table 5.28). Although all 46 patients in the intervention group had received four visits by an occupational therapist (the researcher) only 21(49%) said they had a visit. There were no statistically significant differences between the control and intervention groups for those patients receiving home speech therapy or physiotherapy.

Table 5.26 The number of patients in both groups receiving outpatient therapy at discharge.

	Control (n=43)	Intervention (n=46)			
SPEECH THERAPY	8(19%)	9(20%)	X^2=0.02	df=1	p=0.86
PHYSIOTHERAPY	10(24%)	16(36%)	X^2=1.60	df=1	p=0.20
OCCUPATIONAL THERAPY	3(7%)	14(32%)	X^2=8.24	df=1	p=0.004

Information was missing for 1 patient in the control group and 2 in the intervention group.

Table 5.27 The number of patients in both groups receiving outpatient therapy one year post stroke.

	Control (n=43)	Intervention (n=46)		
SPEECH THERAPY	3(7%)	3(7%)	Fisher's Test	p=1.00
PHYSIOTHERAPY	3(7%)	7(16%)	Fisher's Test	p=0.31
OCCUPATIONAL THERAPY	2(5%)	4(9%)	Fisher's Test	p=0.67

Information was missing for 1 patient in the control group and 2 in the intervention group.

Table 5.28 The number of patients who had therapy at home during the twelve months post stroke.

	Control (n=43)	Intervention (n=46)			
SPEECH THERAPY	3(7%)	2(5%)	Fisher's Test		p=0.67
PHYSIOTHERAPY	4(10%)	4(9%)	Fisher's Test		p=1.00
OCCUPATIONAL THERAPY	1(2%)	21(49%)	X^2=22.34	df=1	p=0.004

Information was missing for 2 patients in the control group and 3 in the intervention group.

The control group received fewer aids to daily living than the intervention group (33 vs 59) (Table 5.29). There was no statistically significant difference between the groups for bath, walking, kitchen or 'other' aids. There was a statistically significant difference between the groups for toilet aids and stair rails, with the intervention group receiving more (3(7%) vs 10(22%) X^2=3.71,df=1,p=0.05 and 5(12%) vs 13(28%) X^2=3.60,df=1,p=0.05 respectively).

Table 5.29 The number of patients in each group who received any of the following aids.

	Control (n=43)	Intervention (n=46)			
BATH AIDS	10(24%)	11(24%)	X^2=0.00	df=1	p=0.99
TOILET AIDS	3(7%)	10(22%)	X^2=3.71	df=1	p=0.05
STAIR RAIL	5(12%)	13(28%)	X^2=3.60	df=1	p=0.05
WALKING AIDS	8(19%)	17(37%)	X^2=3.46	df=1	p=0.06
KITCHEN AIDS	1(2%)	1(2%)	Fisher's Test		p=0.94
OTHER AIDS	6(14%)	7(15%)	X^2=0.01	df=1	p=0.90
TOTAL AIDS	33	59			

Information was missing for 1 patient in the control group.

As with the aids the control group received fewer services on discharge than the intervention group (54 vs 95) (Table 5.30), although there was no statistically significant difference between the groups for each of the services.

Also at one year post stroke the control group received fewer services on discharge than the intervention group (28 vs 52) (Table 5.31). There were no statistically significant differences between the groups for each of the services except District Nurse which fewer of the control group were receiving (3(7%) vs 11(24%) $X^2=4.42$,df=1, p=0.03) (Table 5.31).

Table 5.30 The number of patients in both groups receiving the following services at discharge.

	Control (n=43)	Intervention (n=46)			
HEALTH VISITOR	4(10%)	7(15%)	$X^2=0.65$	df=1	p=0.41
DISTRICT NURSE	8(19%)	14(30%)	$X^2=1.51$	df=1	p=0.21
CHIROPODIST	12(29%)	15(33%)	$X^2=0.16$	df=1	p=0.68
HOME HELP	7(17%)	13(28%)	$X^2=1.68$	df=1	p=0.19
MEALS ON WHEELS	1(2%)	3(6%)	Fisher's Test		p=0.61
SOCIAL WORKER	9(21%)	16(35%)	$X^2=1.92$	df=1	p=0.16
CROSSROADS	0	1(2%)	Fisher's Test		p=1.00
DAYBREAK	0	3(7%)	$X^2=2.90$	df=1	p=0.08
DAY CENTRE	7(17%)	13(29%)	$X^2=1.83$	df=1	p=0.17
STROKE CLUB	4(10%)	8(18%)	$X^2=1.24$	df=1	p=0.26
VOLUNTEER STROKE SCHEME*	2(5%)	2(4%)	Fisher's Test		p=1.00
TOTAL SERVICES	54	95			

Information was missing for 1 patient in the control group for all services.
* Information was missing for 1 patient in the intervention group.

Table 5.31 The number of patients in both groups receiving the following services one year post stroke.

	Control (n=43)	Intervention (n=46)			
HEALTH VISITOR	2(5%)	0	X^2=2.29	df=1	p=0.12
DISTRICT NURSE	3(7%)	11(24%)	X^2=4.42	df=1	p=0.03
CHIROPODIST	4(9%)	7(15%)	X^2=0.58	df=1	p=0.44
HOME HELP	7(17%)	12(26%)	X^2=1.30	df=1	p=0.30
MEALS ON WHEELS	1(2%)	3(7%)	Fisher's Test		p=0.61
SOCIAL WORKER	3(7%)	3(7%)	Fisher's Test		p=1.00
CROSSROADS	0	0			
DAYBREAK	0	2(4%)	Fisher's Test		p=0.49
DAY CENTRE	4(10%)	10(22%)	X^2=2.3	df=1	p=0.12
STROKE CLUB	3(7%)	4(9%)	Fisher's Test		p=1.00
VOLUNTEER STROKE SCHEME	1(2%)	0	Fisher's Test		p=0.47
TOTAL SERVICES	28	52			

Information was missing for 2 patients in the control group for all services.

All patients were invited to comment on their satisfaction with the services they had received. Table 5.32 shows the number of patients who agreed/strongly agreed with the statements. The statistical analysis, using chi square and Fisher's Exact Test, included those who agreed or disagreed with the statements and not those who responded 'does not apply'. There were no statistically significant differences between the control and intervention groups for their answers. For some answers a large number of patients replied that this statement did not apply, for example, 54 patients gave this answer to the statement 'received all necessary support services' even though a total of 149 support services were received on discharge (Table 5.30).

Eleven (26%) of the control group and 4(9%) of the intervention group were readmitted to hospital during the first year post stroke and this is a statistically significant difference (X^2=4.55,df=1,p=0.03). The reasons for admission included cerebral vascular disease, ischaemic heart disease, heart failure and surgery. One patient had four readmissions during the year, two had two readmission and the remainder had one. Of those readmitted there was no statistically significant difference between the two groups for number of days in hospital (z=-1.17, p=0.24) (Table 5.33).

Table 5.32 The number of patients in each group who agreed with the following patient satisfaction statements.

	Control (n=43)	Intervention (n=46)			
Received all the information they wanted about the causes and nature of their illness.	30(77%)	29(67%)	X^2=0.91	df=1	p=0.33
Missing	4	3			
Were happy with the amount of recovery they made.	26(65%)	33(75%)	X^2=1.00	df=1	p=0.31
Missing	4	3			
Satisfied with the outpatient services provided.	17(77%)	30(86%)	Fisher's Test		p=0.48
Does not apply	19	9			
Missing	2	2			
Satisfied with the type of treatment given by therapists.	27(82%)	34(83%)	X^2=0.01	df=1	p=0.90
Does not apply	8	2			
Missing	2	3			
Received enough therapy.	15(47%)	22(54%)	X^2=0.33	df=1	p=0.56
Does not apply	8	3			
Missing	3	2			
Received all the information needed about services.	17(65%)	26(76%)	X^2=0.89	df=1	p=0.34
Does not apply	15	10			
Missing	2	2			
Things (such as aids) were well prepared for return home.	19(86%)	29(83%)	Fisher's Test		p=1.00
Does not apply	19	9			
Missing	2	2			
Receive all the necessary support services.	7(64%)	14(82%)	Fisher's Test		p=0.37
Does not apply	30	24			
Missing	2	3			

Table 5.33 Information on the patients who were readmitted to hospital during the first twelve months post stroke unit discharge.

	Control (n=11)	Intervention (n=4)		
Number of days in hospital				
Median	7	26	z=-1.17	p=0.24
Range	1-42	5-30		

A separate questionnaire for the carers was sent to all patients to be given to their carer as appropriate. Tables 5.34 and 5.35 are the results of the information given by carers of those patients who lived with a spouse, friend, relative, son or daughter, or sheltered accommodation. It excludes those patients living alone or in institutional care. There was no statistically significant difference between the two groups for carers' life satisfaction. Just under half of the carers thought their life satisfaction was poor (8(42%) control and 9(45%) intervention) (Table 5.34).

There was no statistically significant difference between the control and intervention groups for carers' burden as measured by the Relatives Stress Scale (Table 5.35).

Table 5.34 Carers' indication of whether they feel their own life satisfaction is good or poor.

	Control (n=20)	Intervention (n=21)			
Good	11(58%)	11(55%)	X^2=0.03	df=1	p=0.85
Poor	8(42%)	9(45%)			

Information was missing for 1 carer in both the control and intervention groups.

Table 5.35 Results of the Relatives Stress Scale for the control and intervention groups.

	Control (n=20)	Intervention (n=21)		
Median	46	47	z=-0.09	p=0.92
Interquartile Range	31-63	34-57		

Information was missing for two carers in both the control and intervention groups.

5.4 SUMMARY.

Despite random allocation, statistically significant differences were found between the control and intervention group for sex and attendance to day hospital with more females and more day hospital attenders in the intervention group. There were no statistically significant differences between the groups for marital status, home circumstances or levels of function in activities of daily living on admission and discharge.

The median length of time spent by the researcher with each patient in the intervention group was 30 minutes for the first two visits and 25 for the remainder. A total of 92 referrals were made to different agencies such as Stroke Support Groups and Social Services Occupational Therapists while 91 liaisons were made on behalf of the patients to agencies such as Day Hospital and Social Workers.

When comparing the control and intervention groups one year post stroke, there were no statistically significant differences in home circumstances, activities of daily living as measured by the Barthel ADL Index, mood as measured by the Short Geriatric Depression Scale or use of community services (except District Nurse). There were statistically significant differences between the groups

for number of patients who had received toilet aids and stair rails, and the number of patients who had been readmitted to hospital during the twelve months post stroke.

The results found in this chapter will be discussed in relation to the objectives set for the research and in comparison with other research in the next chapter.

CHAPTER 6.

DISCUSSION.

6. DISCUSSION

Four objectives were set when commencing this research. This chapter will discuss each in turn with reference to the results, other studies and with particular attention to problems encountered in attempting to achieve the objectives.

6.1 OBJECTIVE ONE

To conduct a randomized controlled trial allocating patients to a control and intervention group.

6.1.1 Recruitment to the Study.

Calculating the sample size for this study was difficult as no previous studies were available for guidelines of numbers to include or expected outcome (that is, none that had compared occupational therapy with no occupational therapy). An estimate of the magnitude of effect by the intervention was 20% improvement in independence in activities of daily living. It was expected that 40% of the control group would be independent in activities of daily living and that the intervention would enable 60% of the intervention group to be independent in activities of daily living. If it was decided to accept a three in

four chance of detecting (at the p=0.05 level) a difference between the two groups, then using the sample size estimation technique of Boag et al (1971), 180 patients (survivors at one year) would have been required to carry out such a trial. This meant that allowing for mortalities and loss of contact, over 220 patients should have been recruited for this study.

It was apparent that, given the time constraints of the researcher, it would not be possible to recruit 220 patients and therefore different options needed to be considered for the study. It was not possible to extend the researcher's time. Conducting a multicentre study was also not possible as the funding for this research was for the named researcher only. The option chosen was to carry out the project, recruiting as many patients as possible. This would then be considered as primarily a pilot study which would give a first estimate of the unknown treatment difference and thus permit a more accurate design for a longer trial to be carried out. Even a pilot experiment must be of a sensible size and it will sometimes give a conclusive answer by itself (Boag et al 1971).

It was anticipated that 100 patients could be recruited to the study in six months as a total of 272 patients had

been admitted to the stroke units in Cardiff in the previous twelve months. When, at six months, less than 100 patients had been recruited, the recruitment period was extended a further four months - the maximum possible due to the time limitations of the researcher. Even with this extension, it was only possible to recruit 110 patients in ten months. As the recruitment period was from 1st April 1991 to 31st January 1992, one explanation for the low numbers might be seasonal variations. Haberman et al (1981) found that most deaths from cerebrovascular disease occur in February and March (30% more than in the summer) and suggest that there is a similar seasonal pattern for the incidence of cerebrovascular disease.

6.1.2 Collecting Information.

For the purposes of the study information about each patient such as age and sex, their pre-admission status, their function levels on admission and discharge was required. This information was collected by various members of the rehabilitation team including the occupational therapists, medical staff and ward receptionists.

As described in the methodological chapter, all staff agreed to assist in the study and their role was explained

to them. Despite their agreement and additional information provided not all data was collected as requested. Basic information on pre-admission ADL function and mobility was missing for one patient, information on side of stroke, previous stroke and pre-admission mental state was missing for three patients. It is possible that some of this information had to be obtained by carers, relatives or someone who knew the patient well. This may have proved difficult in a small number of cases, which may account for the missing data.

The stroke unit staff also agreed to assess the patient's levels of function in a number of areas, using standardised assessments both on admission and discharge. There were a large number of results missing which suggests that despite agreement, regular encouragement and reminders and reinforcement from senior staff these assessments were not carried out (Table 6.1). The only reason given by staff when questioned on reasons why the assessments were not completed was a lack of time. The Barthel ADL Index can be completed in a very short time whereas all the others take ten to fifteen minutes to complete. Dunn and Lewis (1993) found that less than 20% of geriatric departments in their study completed an admission and discharge Barthel ADL Index and mental test despite agreeing to do so.

Table 6.1 Number of results missing for the Barthel ADL Index, Mini Mental State Examination, Wakefield Depression Scale and Albert's Perception Test.

	Admission (n=110)	Discharge (n=110)
BARTHEL ADL INDEX	7(6%)	13(12%)
MINI MENTAL STATE EXAMINATION	27(25%)	54(49%)
WAKEFIELD DEPRESSION SCALE	38(35%)	56(51%)
ALBERT'S PERCEPTION TEST	32(29%)	51(46%)

The King's Fund (1988) consensus conference on stroke, Wolfe et al (1991) and Collin (1991) suggest that assessment, using standard tools, should be undertaken on all patients at regular intervals and the results should be recorded in the patient's medical notes. It would appear that the staff in the stroke units were not aware of the value of the assessments. Gibbon (1991) and Dummett (1987) suggest that a measurement tool can serve to give direction to the rehabilitation process, facilitate the devising of both short and long-term goals when planning care, can help to determine a person's progress and act as an index to effectiveness of treatment of the individual.

6.1.3 Comparison of Groups at Entry to Study.

The purpose of collecting the information about each of the patients was to enable the researcher to compare both groups following randomization and to establish that both groups were from the same population.

Following the data analysis of the pre-stroke information on the patients, there were no statistically significant differences between the control and intervention groups for age, side of stroke and length of time on the stroke unit. There was a statistically significant difference for sex (males 26(47%) control vs 15(27%) intervention $x^2=4.7$, df=1,p=0.03). Wade et al (1984a) suggest that there is no evidence that one sex makes a better recovery than the other.

Comparison of the results of the Barthel ADL Index, Mini Mental State Examination, Wakefield Depression Scale, and Albert's Perception Test on admission and discharge for both groups was unsatisfactory as so many of the results were missing (Table 6.1). Of those for whom results were available, there were no significant differences between the groups on admission or on discharge for the Barthel ADL Index, the Mini Mental State Examination scores, the

Wakefield Depression Scale scores or the Albert's Perception Test.

Despite random allocation, a statistically significant difference was found between the control and intervention group for attendance to day hospital, with more day hospital attenders in the intervention group (28(55%) control vs 43(78%) intervention $x^2=6.4, df=1, p=0.01$). When setting up the study, discussion had taken place about whether to exclude all day hospital attenders. It was decided that this would limit the numbers of patients for recruitment significantly and that there would not be sufficient numbers to make the study viable. Despite more patients in the intervention group attending day hospital, there were few statistically significant differences between the two groups one year post stroke (Section 5.3).

6.2 OBJECTIVE TWO

To provide regular occupational therapy to the intervention group as appropriate.

The model of occupational therapy used by the researcher was the model of human occupation (Kielhofner 1985) (see section 2.3.3.4). The human occupation model proposes three subsystems, the volition subsystem which guides the

choices of action through personal causation, valued goals and interest, the habituation subsystem which is composed of habits and internalized roles, and the performance system which functions to produce action through skills such as social, cognitive and physical. The model of human occupation provides a structure for assessment and intervention that can be applied to the provision of occupational therapy for stroke patients (Burton 1989). This model provides the therapist with a check list of the influences which operate on the individual engaged in occupational behaviour (Burton 1989).

The median length of time spent by the researcher with each patient in the intervention group was 30 minutes for each of the first two visits and 25 for each of the remainder. The only study showing the amount of time spent by an occupational therapist on a post discharge home visit to the elderly is a recent one by Hassall (1993) who found that 75% of the visits were between 0-30 minutes long and 23% were between 31-60 minutes long. No indication was given of the time spent in indirect contact (for example, making phone calls or liaising with other agencies).

The aims of occupational therapy for patients following a stroke are described in chapter 2 (section 2.3.4.1). Each

is listed here with examples of how the aims were achieved by the researcher.

6.2.1. To assess patients' difficulties.

During each visit, each patient was assessed using observation and interview. Using the model of human occupation the researcher tried to establish the goals, interests, habits and roles of the patients as well as their functional skills. The researcher found that although areas of difficulties were identified the patients often did not want to participate in an intervention programme; for example, patients in residential homes did not wish to become independent in washing and dressing but were happy to have the help available from the staff. Following the assessment the researcher planned with the patient, intervention strategies as appropriate.

6.2.2. To facilitate maximum independence in activities of daily living.

The researcher used a number of techniques to achieve this goal. Patients (and, where appropriate, carers) were instructed in new ways of carrying out a daily living task (for example, the researcher showed a patient an easier

way to put on a jumper so that the patient could do so independently), or were advised on equipment that would enable the patient to be independent (for example, the researcher suggested using Velcro to replace shirt buttons that were too small for the patient to undo independently). The researcher found that although areas of difficulties were identified the patients in residential homes did not wish to become independent in washing and dressing but were happy to have the help available from the staff.

6.2.3. To prevent deformity.

Where appropriate, the researcher gave instruction to the carer (including staff in residential and nursing homes) on how to transfer stroke patients without causing trauma to the shoulder affected by the stroke which is vulnerable to subluxation and dislocation.

6.2.4. To encourage maximum return of function.

Activities that could be carried out in the home environment and that improved range of movement and function were suggested by the researcher to patients. Activities to improve hand function, writing skills and concentration were most frequently suggested.

6.2.5. To help patients to adjust to their disability.

The researcher was asked to clarify questions patients had about stroke, its causes and nature. Two patients expressed great concern and frustration when they were discharged from day hospital/out patient treatment as it marked a point of no further recovery expected by the professionals. Three carers also used the opportunity of the researcher calling to discuss problems they were having with adjusting to the patients' disability.

6.2.6. To alleviate communication problems.

One patient in the intervention group did not speak English. All communication with this patient was through his daughter.

The carers of two patients with severe communication problems and seven other patients with mild to moderate problems were informed of the Volunteer Stroke Scheme which offers support for patients with communication problems following a stroke.

6.2.7. To correct or compensate for perceptual problems.

One patient had perceptual problems that were being dealt with by the day hospital occupational therapist.

6.2.8. To liaise with other members of the multidisciplinary team.

It was in fulfilling this aim that the researcher spent most of the indirect time (see Section 5.2). As the researcher had no budget for equipment or aids, liaison had to be maintained with those who could provide what was required. The researcher liaised with or referred to a number of statutory and voluntary agencies (see Section 5.2). Examples of the liaison included contacting the occupational therapist in social services about promised equipment that had not yet arrived and informing the day hospital occupational therapist of problems that patients had in activities of daily living in their home environment. The researcher liaised with day hospital staff, clinical psychologist, community memory project, community occupational therapist, community physiotherapist, district nurse, general practitioner, disabled resettlement officer, stroke support groups and social workers.

The researcher liaised with the day hospital staff most frequently. As they had been informed that the researcher's input was in addition to theirs, close liaison was required to ensure there was no duplication of intervention.

The researcher made a total of 92 referrals to other agencies (Table 5.14). Sixty (65%) of these referrals were made following the two week visit. Referrals were made to the stroke support groups, social services, disabled resettlement officer, and voluntary agencies such as Women's Royal Voluntary Service, Day Break and the Volunteer Stroke Scheme.

6.2.9. **To provide necessary aids and adaptions.**

As already discussed, the researcher did not have the facilities to provide aids and adaptations as required. However, she did liaise with the social services occupational therapists, carried out joint home visits with them, referred patients to them and provided them with information which assisted them in their assessment.

One patient had received bath aids from social services but was unable to use them because no instruction had been given. Mulley (1988) suggests that one reason why aids are

not used, is that the patient and family may have received little or no instruction in the use of aids. The researcher provided the necessary demonstration and instruction to enable the patient to use them and therefore be independent getting in and out of the bath. Another patient had a grab rail installed by the stairs but had not had the confidence to go up them without supervision. As the patient lived alone, she had no-one to supervise her. The researcher supervised the patient, who gained the confidence to go up and down stairs without supervision.

6.2.10. **To resettle into the community.**

One patient who was living in a residential home wanted to return to the community. He was given advice by the researcher on the type of accommodation that would be most suitable and on the skills he required in order to cope at home.

Another patient, who was living with her son wished to return to her own home. She was given information on useful services including Meals on Wheels and Home Help.

Two patients expressed an interest in returning to work. Both were given a contact name and number for their local

Disabled Resettlement Officer and information about their role. Neither patient made subsequent contact with the officers.

Previous hobbies and interests (as per the model of human occupation) were discussed with all patients. They were asked if they would like assistance to recommence these interests or to take up new ones. Despite the assistance available the majority of patients did not wish to recommence old hobbies.

The researcher gave information to patients about taxi firms that could accommodate wheelchair users, adult education centres that accommodate wheelchair users and voluntary organisations that would take them out or visit them. By providing this information the researcher enabled some patients to participate in social functioning activities.

All patients were informed of the local stroke support groups. Forty four patients (48%) expressed an interest to attend and were referred to the groups (Table 5.14) but only 8(18%) subsequently attended (Table 5.30) and only 4 (9%) were attending a year post stroke (Table 5.31).

By using the model of human occupation the researcher concentrated firstly on patients' goals, motives, interests, habits and roles before functional skills. By discussing these issues with the patients it became obvious that in some situations (in particular with those in residential or nursing homes, or those living with a carer) patients were content with having assistance with activities of daily living and often did not want to learn the skills. This was a large percentage of the intervention group, 45% lived with others and 40% in a residential or nursing home on discharge. One year post stroke 45% were still living with others and 30% were in homes. Similarly Kelly-Hayes (1990) found that 27% of stroke patients were institutionalised one year post stroke.

Andrews (1991), while discussing the effect patients have on the outcome of a study, suggests that patients are people, with their own individual foibles, needs and desires, and the effect of any treatment is much improved if they are determined to improve and very much limited if they have no drive to change their lot. This may be due to depression, previous personality, brain damage (Andrews 1991). There is also the occasional person who finds a life of dependency more attractive than the prospect of

being independent in a less than satisfactory lifestyle (Andrews 1991).

Because occupational therapists set goals in agreement with the patients it was not appropriate for the researcher to use some of her skills to achieve some of the aims of occupation therapy for stroke patients.

6.3 OBJECTIVE THREE

To compare functional levels in activities of daily living, social functioning, mood, use of services, quality of life and if appropriate, carers' burden of all patients in the control group with those in the intervention group one year post stroke.

In order to compare functional levels in activities of daily living, social functioning, mood, use of services, quality of life and if appropriate, carers' burden of all patients in the control group with those in the intervention group one year post stroke, all patients were sent a questionnaire one year post stroke. The questionnaire included The Barthel ADL Index, the Nottingham Extended ADL Scale, the Geriatric Depression Scale (short form) and Pearlman's Quality of Life Scale.

Each of these assessment instruments is described in Chapter 3.

6.3.1 Activities of daily living.

Although there were no statistically significant differences between the control and intervention groups for activities of daily living as measured by the Barthel ADL Index, for each item of the index a greater percentage of the intervention group were independent. This might suggest that the Barthel ADL Index, although a measure of activities of daily living is not sensitive to the effect of the intervention by an occupational therapist. An alternative possible explanation is that occupational therapy with this sample group did not achieve any improvement in activities of daily living.

Although mainly measuring social function the Nottingham Extended Activities of Daily Living Scale does include climbing stairs and feeding oneself, which are also items on the Barthel ADL Index. Table 6.2 shows the number of patients who said they were independent in climbing stairs and feeding themselves. As can be seen by Table 6.2 a larger percentage of patients were indicating that they were independent on the Nottingham Extended ADL Scale than on the Barthel. This is most noticeable for feeding; 37%

of the intervention group indicated they were independent on the Barthel Index and over double that, 76% of the intervention group, indicated it on the Nottingham Extended ADL Scale. This raises questions over the reliability and sensitivity of both these tests and their ability to be used as measures of outcome following occupational therapy. Both tests use similar but not identical phrasing. When using the Nottingham Extended ADL Scale, there was a statistically significant difference between the two groups for feeding (X^2=4.0,df=1,p=0.04) which was not present when using the Barthel ADL Index. Despite the differences in the two scales, there was a high correlation between them (correlation coefficient = 0.7, p=0.001).

Table 6.2 Comparison of responses for Barthel ADL Index and Nottingham Extended ADL Scale (EADL) for stairs and feeding.

	Control (n=43)	Intervention (n=46)			
Barthel: Stairs	8(19%)	9(20%)	X^2=0.9	df=2	p=0.63
EADL: Stairs	13(30%)	12(26%)	X^2=0.1	df=1	p=0.66
Barthel: Feeding	15(35%)	17(37%)	X^2=1.1	df=2	p=0.57
EADL: Feeding	24(56%)	35(76%)	X^2=4.0	df=1	p=0.04

6.3.2 Social function

There were no statistically significant differences between the control and intervention groups for social function activities as measured by the Nottingham Extended ADL Scale. The median score for both groups was very low (2 for control group and 3 for the intervention group). This suggests that this group of stroke patients had very poor social functioning which is similar to findings in other studies (Astrom et al 1992 and Anderson 1992). It is disappointing however, that despite the intervention, the intervention group had not got a higher score. The possible reasons for this are further discussed in Section 6.4.

Astrom et al (1992) and Anderson (1992) suggest that a marked social deterioration often follows a stroke and many stroke survivors do not return to normal social life even after physical disability has ceased to be a serious obstacle (Labi et al 1980, Ebrahim 1990 and Niemi et al 1988). Price (1990) suggests that poor social functioning is probably a result of depression rather than a cause of it.

Belanger et al (1988) found a decrease in the practice of activities such as paid work, housework, management of

personal affairs and leisure activities six months after discharge. Atler and Gliner (1989) interviewed thirty male patients one year post stroke to establish their post stroke activity. They found that passive activities were least likely to be reduced by the stroke. They reported an increase in watching television and a decrease in travelling and home maintenance.

6.3.3 **Mood.**

There were no statistically significant differences between the control and intervention groups for mood as measured by the Short Form Geriatric Depression Scale. In both groups the majority had a score indicative of depression. House (1987) suggests that depression is likely to be almost twice as common among patients in the first year after stroke as among the normal elderly population. Wade et al (1987b) found that over 50% of patients depressed at three weeks remained so at one year and Robinson et al (1984) found that the duration of depression following stroke is more than six months and that the prevalence of major depressive symptoms increase steadily for the first six months post stroke. They also found that depression had an important impact on functional recovery and rehabilitation (Robinson et al 1984).

Robinson and Price (1982) found that depressive disorders were more common during the period from 6 months to 2 years and that there was no correlation between the degree of physical or cognitive impairment and the severity of depression. Collin et al (1987) also found a high proportion (42%) of patients, between one and two years post stroke, to be depressed. Johnson (1991) suggests that the concept of "post-stroke depression" may be too broad and nonspecific and that aetiological factors have not yet been adequately appraised.

Towle (1988) in a study looking at participation in extended activities of daily living (such as shopping, social outings) and depressed mood after stroke, found that some patients were often capable of carrying out an activity but never actually did it. As the patients were depressed they were unwilling to do much for themselves. Similarly Schubert et al (1992b) found that depression lowered functional ability by increasing fatigue, hopelessness and decreasing motivation.

6.3.4 **Patient Satisfaction.**

The questionnaire contained eight patient satisfaction questions relating to information and services provided while in hospital and since discharge. There were no

statistically significant differences between the two groups. Twenty three percent of the control group and thirty three percent of the intervention group felt that they had not received all the information about the causes and nature of their illness. This is similar to other findings. Hanger and Mulley (1993) when trying to establish the type and frequency of questions asked about stroke by patients, relatives and caregivers, found that nearly 25% needed more information about the nature of stroke. Pound et al (1994) also found that 28% of stroke patients at six months post stroke were dissatisfied with the amount of information they had been given about the causes and nature of their illness.

Hanger and Mulley (1993) found that the other common inquiries concerned help at home (with many expressing concern about their current level of community support), requests for information about stroke clubs, speech difficulties, rehabilitation, personality changes and depression. Hanger and Mulley (1993) suggest that not enough information is given to stroke families by hospital staff. More than a third of the people making inquiries to a stroke information centre were concerned about their ability to cope at home after discharge or the lack of support services organised in preparation for discharge (Hanger and Mulley 1993).

Thirty five percent of the control group and twenty five percent of the intervention group were dissatisfied with the amount of recovery they had made (Table 5.32). Again this is similar to what Pound et al (1994) found, that is, 31% were dissatisfied with the amount of recovery they had made since their illness.

Over half (53%) of the control group and less than half (46%) of the intervention group were dissatisfied with the amount of therapy they had received, which again is similar to the findings of Pound et al (1994). They found that 54% of patients were dissatisfied with the amount of therapy (physiotherapy, occupational therapy or speech therapy) they had received. Pound et al (1994) suggest that as patients are often told that there is nothing they or the health care professions can do to aid recovery after a certain period, it may be that people who say that they have not received enough therapy are expressing disappointment with the amount of recovery they have made, and are focusing this disappointment on the only treatment they have received.

Twenty three percent of the control group and 14% of the intervention group were dissatisfied with the outpatient services they received (Table 5.32). Pound et al (1994) found that 26% of stroke patients were dissatisfied with

outpatient services. While 33% were dissatisfied with their discharge preparation (Pound et al 1994), in comparison with 14% of the control group and 17% of the intervention group. The fact that patients were dissatisfied with the services they received after discharge supports the calls to improve these services.

6.3.5 Use of Services.

Although there were no statistically significant differences between the control and intervention groups for use of the various services, the intervention group were using more services then the control group (95 vs 54) at discharge (Table 5.30). Both groups were using fewer services one year post stroke, with the intervention group using 52 and the control group 28 (Table 5.31).

Cochrane (1983) suggests that many elderly people can continue to look after themselves if they receive the care of nurses, bath attendants, home helps and meals on wheels. Garraway et al (1981b) found that for community based services, the level of use was not closely related to outcome expressed as independence or dependence in performing activities of daily living. They found that the overall levels of contact with virtually all services were low and that by far the most frequent contribution

was made by the home help service (Garraway et al 1981b). Similarly in the present study, the service used most was the home help service, with 7 (17%) of the control group and 12 (26%) of the intervention group using this service one year post stroke (Table 5.31).

6.3.6 Quality of Life.

Fitzpatrick et al (1992) suggest that the term quality of life is misleading as it suggests an abstract and philosophical approach, but most approaches used in medical contexts do not attempt to include more general notions such as life satisfaction or living standards and tend rather to concentrate on aspects of personal experience that might be related to health and health care. For the purpose of this study quality of life was considered as patients' life satisfaction. Pearlman's Scale was used to measure this.

Although there was no statistically significant difference between the control group and the intervention group, it is worth noting that 63% of the control group and 66% of the intervention group thought their life satisfaction was good. These results are in spite of low scores in activities of daily living, social functioning and depression. This is similar to the findings of others.

Pearlman and Uhlmann (1991), in a study looking at the quality of life of elderly, chronically ill outpatients, found that these persons had adapted to their life situations in so far as they rated their quality of life as acceptable.

However, Ebrahim (1990) suggests that quality of life is poor in many patients despite good recovery and Niemi et al (1988) found that in spite of a good recovery in terms of discharge from hospital, activities of daily living, and return to work, the quality of life of most patients had not been restored to the prestroke level. It is possible that these opposing comments could be due to different interpretations of quality of life.

The Royal College of Physicians (1992) suggest that there is difficulty in assessing the quality of long-term care. The goal of such care should be high quality of life for residents, but this is difficult to define and elusive to measure, particularly amongst the more frail long-term care residents (Royal College of Physicians 1992). They suggest that long-term care should aim to simulate ordinary life at home through an agreed flexible programme for each resident to ensure that an agreed form of address is used, personal clothes are worn, meals are provided according to preference, and an appropriately organised

programme of recreational and cultural activities is available if desired. The researcher found, when relaying residents' preference for recreational and cultural activities, that little effort was made to enable the resident to carry these out or that the information was not passed on to other members of staff.

6.3.7 **Aids to Daily Living.**

In the area of provision of aids to patients there was a statistically significant difference between the control and intervention group (Table 5.29). The total number of aids (bath, toilet, walking, kitchen, and grab rails) that the control group had received was 33 whereas 59 aids had been received by the intervention group. One explanation for this could be that the intervention group needed more in order to be independent. This is unlikely as there were no significant differences between the groups in activities of daily living on discharge (Section 6.1.3).

The most likely explanation of the difference in the number of patients who had received aids is that the researcher, although unable to supply these, was able to ensure that, if required, they were ordered. An occupational therapist can establish that an aid is needed and ensure that the correct aid is provided and used

correctly and safely (Mulley 1988). A considerable amount of the referring and liaising carried out by the researcher was to the suppliers of the aids (social services occupational therapists and day hospital occupational therapists).

6.3.8 **Readmission to Hospital.**

There was a statistically significant difference between the two groups for readmission during the first year post stroke. Eleven (26%) of the control group were readmitted, whereas only 4 (9%) of the intervention group were readmitted (X^2=4.55,df=1,p=0.03). These findings are similar to those of Townsend et al (1988). They carried out a trial looking at the benefit of post discharge care attendant service. Their results showed that lack of support in the community resulted in a higher than necessary readmission rate for some patients. They suggest that such a service results in a reduced admission rate, particularly in the longer run and that this benefit is greatest for those living alone and those over 85 years (Townsend et al 1988).

The largest part of the direct health care costs associated with stroke results from the treatment that is provided on a hospital inpatient basis (Office of Health

Economics 1988). Therefore serious consideration should be given to costs saved by providing community support to stroke patients following discharge.

6.3.9 Carers' Burden.

There were no statistically significant differences between the two groups for carers' stress as measured by the Relatives Stress Scale. The median score for the control group was 46 and for the intervention group was 47. These scores reflect the carers' responses when asked how they rated their own life satisfaction. Eight (42%) of the control group carers indicated that their life satisfaction was poor as did 9(45%) of the intervention group carers.

Allen et al (1988) suggest that following a stroke, it is easy to concentrate upon the patient to the exclusion of the family. Teraoka and Burgard (1992) suggest that family counselling and education are an essential part of stroke rehabilitation. They also suggest that it is important for the rehabilitation team to incorporate the family into the careful planning for the return home for a smoother less stressful transition and readjustment (Teraoka and Burgard 1992).

6.4 OBJECTIVE FOUR

To evaluate continued occupational therapy for stroke patients after hospital discharge from a stroke unit.

As can be seen from the results (Chapter 5) and Section 6.3, it would appear that occupational therapy input to stroke patients after hospital discharge from a stroke unit, appeared to have little impact on function outcome when comparing the control and intervention groups. There were few statistically significant differences between the two groups one year post stroke. This section addresses the many reasons why this may have occurred.

6.4.1 Image of Occupational Therapy.

One reason for the results of this study may be the poor image of occupational therapy. Joice and Coia (1989) suggest that some degree of ignorance exists as to the full extent of the skills that can be provided by occupational therapy. It does not have the same profile or understanding as other therapies, for example, physiotherapy or speech therapy. The title of the profession may not have given patients an insight into what problems this health professional (the researcher) may have been able to help with. This may explain the

number of patients who felt that they had no problem that could be helped by an occupational therapist, when the researcher called, despite having a letter saying that help could be given to enable the patient to carry out everyday things. Twenty five (51%) of the patients in the intervention group stated that they had not had home occupational therapy during the year post stroke (Table 5.28). This was in spite of being seen four times and receiving correspondence from an occupational therapist (the researcher).

This is similar to the findings of McAvoy (1992), who, in a study investigating patients' awareness of occupational therapy, following domiciliary visits, found that 32% were not aware of being seen, despite many of them having been visited on numerous occasions and provided with various pieces of equipment and alterations.

For the duration of the study the researcher did not wear a uniform. McAvoy (1992) suggests that the wearing of one could make an occupational therapist more distinctive. McAvoy (1992) found that only 13% of patients seen in an outpatient clinic did not remember seeing the occupational therapist despite wearing a uniform, defining the role of the occupational therapist and explaining her actions fully to each patient. If the researcher had worn a

uniform while visiting the patients more may have indicated that they had been visited.

McAvoy (1992) suggests that the patients did not view the therapist's intervention as significant or worth remembering. While the therapist might view the provision of a grab rail by a toilet as a major step in improving the patient's level of independence and safety, and could even display such improvement on a relevant ADL measurement scale, the patients may have a different viewpoint and feel that they were managing perfectly well by pulling on the radiator to get themselves off the toilet.

6.4.2 **Timing of Intervention.**

Evaluation of the effects of rehabilitation has to take into account the spontaneous recovery that occurs after a stroke (Ebrahim 1990). Many authors suggest that the bulk of recovery of physical ability in self-care appears to occur over the first six months and is most rapid over the first three months (Wade et al 1985d, Allen et al 1988, Wade 1988b, Ebrahim 1990, Kelly Hayes 1990 and Anderson 1992). Ottenbacher and Jannell (1993) suggest that functional improvement following a stroke appears to

relate to early treatment but not to the duration of treatment.

The median number of days from the stroke occurring to admission to stroke unit was 10 days for the control group and 11.5 for the intervention group (Table 5.3). The median length of stay on the stroke unit for the patients in this study was 50 days (Table 5.3). This would suggest that the occupational therapy intervention began after two and a half months post stroke (the first visit was two weeks post discharge). It could be argued that most of the recovery had occurred by this time and that the effect of the intervention after this time was too small to be measured by the Barthel ADL Index.

Tangeman et al (1990) carried out a study looking at rehabilitation after the bulk of recovery had taken place, approximately one year post stroke. Their results are not comparable with this study as the intervention and patient groups were different. Tangeman et al (1990) studied intensive rehabilitation approximately one year post stroke. The rehabilitation consisted of two hours of individual occupational therapy and physiotherapy four days a week and one day of group activities for four weeks. Only those living in the community and mobilizing unaided were accepted into the study. At the end they

demonstrated a significant improvement in weight shift, balance, and activities of daily living. As the patients were recruited via the local media the authors felt the subjects were a motivated group.

6.4.3 Measuring the Benefits of Occupational Therapy.

Fricke (1993) suggests that the use of assessments are valuable in occupational therapy research. Although each individual assessment used in this study's questionnaire has been tested for reliability for stroke patients, none of them was designed exclusively to assess occupational therapy. No assessments exist that specifically assess occupational therapy therefore; for reasons discussed in chapter 3, the Barthel ADL Index, the Nottingham Extended ADL Scale and the Short Form Geriatric Depression Scale were included in the questionnaire.

Gompertz et al (1993) have recently conducted a study to investigate the test-retest reliability of various well-known measures of stroke outcome (the Barthel ADL Index, the Extended ADL Scale) and to compare the reliability of mood measures (Geriatric Depression Scale - short form) by sending out two identical questionnaires containing these scales at two week intervals to a group of stroke patients. They found that the Extended ADL scale had

predominantly good or very good agreement, the items of the Barthel Index had mostly good agreement and the GDS had a number with only fair or moderate agreement.

When comparing outcomes in groups of patients, the unreliability of a test instrument would affect the performance of these measures by adding a spurious element to the actual variance of the population being studied (Gompertz et al 1993). This would make it harder to identify statistical significance, making the instruments less likely to detect real differences between populations. The use of these scales as outcome measures may be associated with failure to detect clinically important differences in controlled trials. Gompertz et al's (1993) findings may be the reason why few statistically significant differences were found between the control and intervention groups of this study one year post stroke.

6.4.4 **Multidisciplinary Team vs One Profession.**

One possible explanation of the disappointing results of this study could be that occupational therapy in isolation does not have the same impact as occupational therapy as part of a multidisciplinary team. Although the researcher

did liaise with other professionals, she was not part of a rehabilitation team.

Young and Forster (1993) suggest that disabled stroke patients are more likely than others (such as patients with orthopaedic conditions) to require more intensive involvement of the whole multidisciplinary rehabilitation team. Also Falconer et al (1993) suggest that the interdisciplinary team approach is the ideal model for providing comprehensive management of stroke disability.

The Office of Health Economics, (1988) suggest that the provision of an adequate domiciliary-care service would seem to be an essential part of the overall management of stroke patients. They suggest that a community service should include physiotherapists and occupational therapists.

Wade (1990) suggests that an ideal stroke service should ensure a smooth transition from active rehabilitation to long term support. Perhaps this support should be provided by the staff in the stroke unit, including the occupational therapist.

6.4. Occupational Therapy Research.

Although a randomized controlled trial (quantitative procedure) was the study design selected for this research, the results could suggest that this was not the only appropriate method of evaluating the effects of occupational therapy. Ethridge and McSweeney (1970) suggest that qualitative and ethnographic procedures are often more appropriate to the questions facing occupational therapists and that experimental research is quite rare in occupational therapy.

Pound et al (1994), Robertson (1988) and Kielhofner (1985) suggest that consideration should be given to qualitative techniques. Pound et al (1994) suggest that qualitative research might throw more light on the complex reasons why patients want more therapy and on their expectations of recovery.

Robertson (1988) suggests that considering that occupational therapy's field of expertise is to do with meaningful or purposeful activity in relation to the health of patients, it would seem that the qualitative approach should be an ideal one because phenomena such as meaning and purpose do not lend themselves readily to quantitative analysis.

Kielhofner (1985) suggests that there is a special harmony between the concerns of the occupational therapist and the methods of qualitative research as both focus on the realities of every day life and attempt to gear their techniques to the realities of the people involved.

Another contributing factor to the results of this research could be that the researcher was trying to assess the effect of occupational therapy as a whole. It might have been more useful if one area of daily living activities had been addressed and measured. Walker and Lincoln (1990), for example, looked at the reacquisition of dressing skills after stroke and Parker and Thorslund (1991) looked at the use of technical aids by the elderly.

Atler and Gliner (1989) suggest the need for occupational therapists to be involved in post stroke rehabilitation, in particular in the exploration of leisure skills and roles and treatment to increase involvement in home maintenance.

CHAPTER 7.

CONCLUSIONS.

7. CONCLUSIONS.

In 1981 Garraway et al suggested that stroke rehabilitation is a continuing process which extends well beyond the acute phase in hospital and that there is an important role for community and hospital services in providing support for stroke patients and their families in their own homes. It was such statements and knowledge of local practises that inspired this research. Follow-up services for stroke unit patients were disjointed with no set guidelines or criteria for referral to services. It was hoped that by conducting this study that comment could be made on the influence of rehabilitative intervention by an occupational therapist on the long term outcome of stroke patients following discharge from a stroke unit.

The objectives of this research were achieved in that a randomized controlled trial was conducted, regular occupational therapy was provided to the intervention group as appropriate, comparisons were made of the two groups a year post stroke and the continued occupational therapy was evaluated.

The number of patients recruited to the study is one of its limitations, and the findings reflect this. It appears that stroke unit staff need further education and

persuasion that carrying out standardised assessments should become routine practice.

Because the patients continued to have problems after discharge which were highlighted and addressed by the researcher, it is important that patients following discharge from a stroke unit continue to have support. Although for the purposes of this study the input was by an occupational therapist consideration should be given to the skills of all health professionals in the rehabilitation team.

By providing occupational therapy to the intervention group for the first six months post discharge, at one year post stroke the intervention group had received more stair rails and toilet aids. This may be due to the researchers ability to highlight a need and liaise with the providers of aids. The intervention group also had fewer readmissions to hospital. The intervention group also had the benefit of referrals to other services, services with whom the researcher liaised. The investment in a follow-up service could yield considerable benefits by keeping patients at home and thus reducing demand for unnecessary readmissions to hospital.

There were no other statistically significant differences between the two groups as measured by outcome measures for

activities of daily living, social functioning, mood, use of services, quality of life and carers' burden.

If the researcher were to carry out this project again further consideration would be given to alternative study designs and qualitative research methods. Structured interviews and observations one year post stroke would provide more information than that received from the questionnaires; however the researcher is aware of the limitations that funding and time placed on this study. Also further consideration would be given to the delivery of the occupational therapy post discharge with reference to frequency and timing, quantity, and the model of occupational therapy being used. When commencing the research the researcher had little knowledge of the various models of occupational therapy. A greater knowledge of the model used would have assisted in the delivery of the occupational therapy. Throughout the study the researcher was aware of the limited support available from colleagues due to the fact that the researcher was not a member of any multidisciplinary team. Also liaison with other professionals when referring patients to them would have been easier if the researcher had belonged to a rehabilitation team. Consideration would also be given to the benefit of stroke unit staff carrying out the intervention. The patients may have responded differently

to staff they already knew and had worked with while in the stroke units.

Further research could be carried out looking at the effect of providing intervention to non-stroke unit patients following discharge, that is, those who are discharged directly from acute medical wards. These patients may also benefit from support following their stroke. Research could also be carried out to evaluate a follow-up service provided by the stroke unit staff. The patients may respond differently to this intervention as they would be familiar with the staff, and the staff would know their strengths and needs. Further research could include evaluating the influence of providing occupational therapy to improve one aspect of patients' lives such as leisure or dressing skills. This would involve concentrating the intervention on the chosen aspect or skill. A complex area for further research is that of the influence of patients' personality and motivation on the rate and amount of recovery and improvement following rehabilitation. Finally, further research could be carried out to establish alternative qualitative and quantitative methods of measuring the effect of occupational therapy. Currently the assessments used to measure occupational therapy have not been developed by occupational therapist nor have they been developed for the exclusive purpose of measuring the effects of occupational therapy.

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APPENDIX A.

Stroke Unit Summary Sheet and Assessment Pack.

STROKE UNIT DATA

NAME:

ADDRESS:

HOSPITAL (1 = SDH/UHW; 2 = Sully) I_I

HOSPITAL NO.

DATE OF ONSET OF CVA .....

AGE (on admission) I_I_I_I

SEX: (1 = male) I_I
(2 = female)

MARITAL STATUS:
(1 = single)
(2 = married) I_I
(3 = divorced/separated)
(4 = widowed)

CVA to S.U. INTERVAL I_I_I_I

PAST MEDICAL HISTORY
(0 = no; 1 = yes)

Previous CVA	I_I
TIA/RIND	I_I
A Fib	I_I
Hypertension	I_I
Diabetes	I_I
Current smoker	I_I

PREMORBID STATUS

ADLs (0 = dependent)	
(1 = needs help)	I_I
(2 = independent)	
Mobility (0 = immobile)	
(1 = walk c help)	I_I
(2 = walk unaided)	
Mental State (0 = confused)	I_I
(1 = alert)	
Continence (0 = incont/cath)	
(1 = occ incont)	I_I
(2 = cont)	

LIVING
(1 = alone)
(2 = with spouse)
(3 = with other pensionner) I_I
(4 = with children)
(5 = sheltered housing)
(6 = residential home care)
(7 = nursing home care)

STATUTORY SERVICES
(0 = no; 1 = yes)

Home help	I_I
Meals on wheels	I_I
Community nurse	I_I
Day hospital	I_I

SITE OF CVA
(1 = right carotid)
(2 = left carotid) I_I
(3 = vertebro-basilar)

HEMIANOPIA
(1 = absent)
(2 = present) I_I

HOSPITAL-ACQUIRED EVENTS
(0 = no; 1 = yes)

Shoulder injury	I_I
Depression .	I_I
Chest infection	I_I
UTI	I_I
Falls	I_I
Pressure areas	I_I
DVT	I_I
Other	I_I

DISCHARGE
(0 = RIP on stroke unit)
(1 = to previous home) I_I
(2 = to new accommodation)

NOW LIVING
(1 = alone)
(2 = with spouse)
(3 = with other pensionner)
(4 = with children) I_I
(5 = sheltered housing)
(6 = residential home care)
(7 = nursing home care)

Date of discharge .....

Time in hospital (days) I_I_I_I

FOLLOW-UP (0=no; 1=yes)

Day Hospital	I_I
Out-patient O.T.	I_I
Out-patient Physio	I_I
Out-patient Speech T.	I_I

DATE | | | | | | |

PATIENT'S NAME:

BOWELS
0 = incontinent
1 = occasional accident
2 = continent

BLADDER
0 = incontinent or catheterised & unable to manage
1 = occasional accident (max 1x per 24 hours)
2 = continent (for over 7 days)

GROOMING
0 = needs help
1 = independent, face / hair /teeth / shaving

TOILET USE
0 = dependent
1 = needs some help, but can do something
2 = independent (on & off, dressing, wiping)

FEEDING
0 = unable
1 = needs help cutting, spreading butter etc.
2 = independent

TRANSFER
0 = unable
1 = major help (1-2 people, physical)
2 = minor help (verbal or physical)
3 = independent

MOBILITY
0 = immobile (1 = 1 physio or 2 people)
1 = wheel chair independent including corners etc.
2 = walks with help of 1 person (verbal or physical)
3 = independent (but may use any aid, e.g. stick)

DRESSING
0 = dependent
1 = needs help, but can do about half unaided
2 = independent

STAIRS
0 = unable
1 = needs help (verbal, physical, carrying aid)
2 = independent up and down

BATHING
0 = dependent
1 = independent

TOTAL

SUMMARY:

ADMISSION ASSESSMENT:

Date
Barthel Score
Mini Mental Score
Depression Score
Albert's Test

DISCHARGE ASSESSMENT:

Date
Bathel Score
Mini Mental Score
Depression Score
Albert's Test

COMMUNICATION
(1=yes, 2 = no)
DYSPHASIA
Receptive
Expressive
Dysarthia

SWALLOWING
N.G. Tube
Gastrostomy
Supervised
Unsupervised

Admis. Disc.

SITTING BALANCE:
0 = cannot sit unsupported
1 =decreased righting reflexes
2 = copes with deplacement

MINI MENTAL STATUS

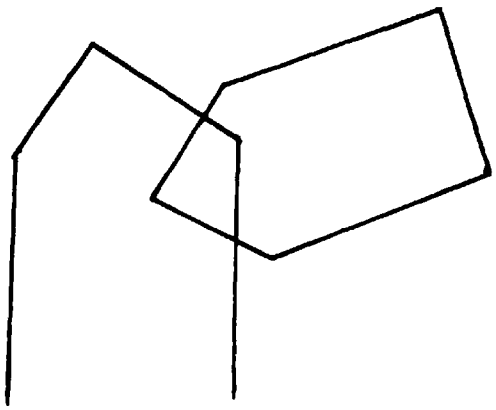
PATIENT NO. |_|_|_|

Patient's name:

Necessary materials; pencil, three sheets of paper

1 What day of the week is it? 2 What is the date today? 3 What is the month? 4 What is the season? 5 What is the year?	**These can asked informally**	|_| |_| |_| |_| |_|	|_| |_| |_| |_| |_|
6 Where are we now? 7 What floor are we on? **(or ward)** 8 In which town are we? 9 In county/district are we? 10 In which counrty are we?		|_| |_| |_| |_| |_|	|_| |_| |_| |_| |_|
11 Repeat the following words LEMON, KEY, BALLOON 12 **(The examiner should pronounce the words at a rate of** 13 **one per second. In case of difficulties repeat up to 5 times.)**		|_| LEMON |_| KEY |_| BALLOON	|_| |_|
14 15 Subtract 7 from 100 and make 5 subtractions. 16 17 **Each correct subtraction = tick** 18 **eg. 93,88,81,74,67 = 4 correct.**		|_| |_| |_| |_| |_|	|_| |_| |_| |_| |_|
19 20 Can you remember the three words you just said? 21		|_| LEMON |_| KEY |_| BALLOON	|_| |_|
22 What is this? **Show a pencil.** 23 What is this? **Show a watch.** 24 Repeat the following, "No ifs, ands or buts"		|_| |_|	|_| |_|
25 Follow a three stage command. "Take this piece 26 of paper, fold it in half and put it on the floor." 27 **Give all the instrctions in one go.**		|_| |_|	|_| |_|
28 Read and obey what is written on this piece of paper. ("Close your eyes")		|_|	|_|
29 Write a sentence of your choice on this piece of paper.		|_|	|_|
30 Copy this drawing on a piece of paper.		|_|	|_|

TOTAL CORRECT |_|_| |_|_|
ADMISSION DISCHARGE



Copy must have 10 corners and quadrilateral in the middle.

WAKEFIELD SELF - ASSESSMENT DEPRESSION INVENTORY

Scoring on each item is 0,1,2, or 3 according to the response given. Total score is the addition of item scores.

Read these statements carefully, one at a time, and note the response which best indicates how the patient is. It is most important to indicate how you are NOW, not how you were, or how you would hope to be.

(a) YES, DEFINITELY (b) YES, SOMETIMES

(c) NO, NOT MUCH (d) NO, NOT AT ALL

1. I feel miserable and sad ☐ ☐
   (a = 3,b = 2,c = 1,d = 0)

2. I find it easy to do the things I used to ☐ ☐
   (a = 0,b = 1,c = 2,d = 3)

3. I get very frightened or panic feelings for apparently no reason at all. ☐ ☐
   (a = 3,b = 2,c = 1,d = 0)

4. I have weeping spells, or feel like it ☐ ☐
   (a = 3,b = 2,c = 1,d =0)

5. I still enjoy the things I used to ☐ ☐
   (a = 0,b = 1,c = 2,d = 3)

6. I am restless and can't keep still ☐ ☐
   (a =3,b = 2,c = 1,d = 0)

7. I get off to sleep easily without sleeping tablets ☐ ☐
   (a = 0,b = 1,c = 2,d = 3)

8. I feel anxious when I go out of the house on my own. ☐ ☐
   (a = 3,b = 2,c = 1,d = 0)

9. I have lost interest in things ☐ ☐
   (a = 3,b = 2,c = 1,d = 0)

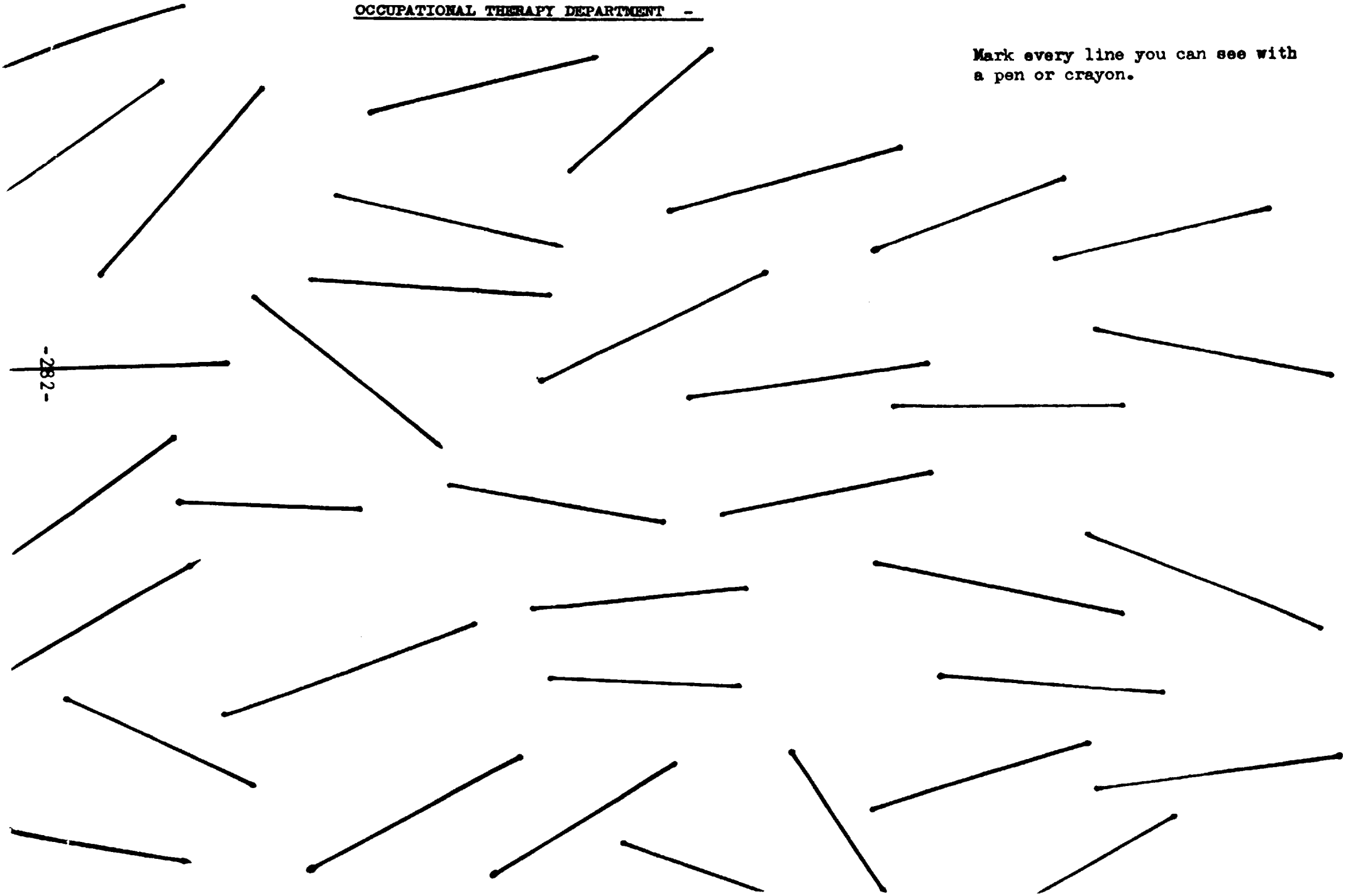
10. I get tired for no reason ☐ ☐
    (a = 3,b = 2,c = 1,d = 0)

11. I am more irritable than usual ☐ ☐
    (a = 3,b = 2,c = 1,d =0)

12. I wake early and then sleep badly for the rest of the night. ☐ ☐
    (a = 3,b = 2,c = 1,d = 0)

OCCUPATIONAL THERAPY DEPARTMENT -

Mark every line you can see with a pen or crayon.



APPENDIX B.

Discharge Correspondence.
Letter to Patient.
Letter to General Practitioner.

Coleg Meddygaeth Prifysgol Cymru

University of Wales College of Medicine

University Department of Geriatric Medicine,
Cardiff Royal Infirmary (West Wing)
Newport Road, Cardiff CF2 1SZ

Tel: 0222-492233 — Ext. 5291
Fax: 0222-483968 484668

Professor Ken Woodhouse
Dr. Gwyn Seymour
Dr. Alan Sinclair
Dr. Tony Bayer
Dr. Dee Jones

AJB/bbc.corr2204.001

Dear

Following your rehabilitation on the Stroke Unit, we are interested in looking at the benefits of continuing therapy now that you have left hospital.

Susan Corr (an Occupational Therapist) is following up patients after their hospital discharge to see how they are getting on and to give advice and help with managing everyday activities. This is in addition to any other follow up arrangements already made.

She will be in contact with you to make an appointment to come and visit you at home within the next 1-2 weeks, and will also see you again in 2 months and 6 months time.

As well as advising on practical issues, she will be able to help you with contacting other services if appropriate.

She will be very happy to answer all your questions when she visits or she may be contacted by telephone at 711711, extension 5149.

With very best wishes

Yours sincerely

Dr Paul Finucane
Senior Lecturer and Consultant Physician

Coleg Meddygaeth Prifysgol Cymru

University of Wales College of Medicine

University Department of Geriatric Medicine,
Cardiff Royal Infirmary (West Wing)
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Tel: 0222-492233 — Ext.
Fax: 0222-483968

Professor Ken Woodhouse
Dr. Gwyn Seymour
Dr. Alan Sinclair
Dr. Tony Bayer
Dr. Dee Jones

AJB/bbc2204.001

Dr.

Dear Dr.

As you will know, your patient was recently discharged from hospital following rehabilitation after a stroke.

Ms. Susan Corr, an Occupational Therapist, is currently following up some stroke patients after discharge to see if she can further improve their day to day functioning. She can be contacted at Llandough Hospital (ext. 5149) and will be very happy to discuss any stroke related problems with you.

Yours sincerely

DR ANTONY BAYER

APPENDIX C.

Questionnaires and Correspondence.

Patient's Letter.
Patient's Questionnaire.
Carer's Letter.
Carer's Questionnaire.

Coleg Meddygaeth Prifysgol Cymru

University of Wales College of Medicine

University Department of Geriatric Medicine,
Cardiff Royal Infirmary (West Wing)
Newport Road, Cardiff CF2 1SZ

Tel: 0222-492233 — Ext.
Fax: 0222-483968

Professor Ken Woodhouse
Dr. Gwyn Seymour
Dr. Alan Sinclair
Dr. Tony Bayer
Dr. Dee Jones

AJB/bbs.2204

Dear

Following your rehabilitation some months age in the Stroke Unit, we are interested in finding out how you are now.

It would be very helpful if you would complete the enclosed questionnaire and return it in the stamped addressed envelope provided. If you are unable to complete all the forms yourself, please ask someone to help you.

There is also a brief questionnaire addressed to a relative or friend (someone else who knows you well) and it would be helpful if you could pass this on.

Your answers will help us to develop our services for stroke patients more effectively in the future. If there are any specific problems you feel we may be able to help, then please let us know.

With many thanks for your help and co-operation.

Yours sincerely

DR ANTONY BAYER

SOUTH GLAMORGAN STROKE OUTCOME PROJECT

Basic Details

Please give us some basic information about yourself, so we won't duplicate our files

Name

Address

Post Code

Telephone

Todays date

day *month* *year*

Date of Stroke

day *month*

Tick the box that applies to you, like this ✓

When you were **FIRST** discharged from the Stroke Unit where did you go to live ?

Alone	☐	1
With Husband / Wife	☐	2
Wth Friend / Relatives	☐	3
With Son / Daughter	☐	4
Sheltered Housing	☐	5
Residential Home	☐	6
Nursing Home	☐	7
Other (Specify)	☐	8
		9

Where do you live **NOW** ?

Alone	☐	1
With Husband / Wife	☐	2
Wth Friend / Relatives	☐	3
With Son / Daughter	☐	4
Sheltered Housing	☐	5
Residential Home	☐	6
Nursing Home	☐	7
Other (Specify)	☐	8
		9

SELF - CARE ABILITIES

These are some questions about your ability to look after yourself. They may not seem to apply to you. Please answer them all. Tick the box that applies to you, like this ✓

In the bath do you ?

Remember - tick one box only

Manage on your own ? ☐ 1
Need help getting in and out ? ☐ 2
Need other help ? ☐ 3
Never have a bath or shower ? ☐ 4
Need to be washed in bed ? ☐ 5
9

Do you climb stairs at home ?

Remember - tick one box only

Without any help ? ☐ 1
With someone carrying your frame ? ☐ 2
With someone encouraging you ? ☐ 3
With physical help ? ☐ 4
Not at all ? ☐ 5
Don't have stairs ? ☐ 6
9

Do you get dressed ?

Remember - tick one box only

Without help ? ☐ 1
Just with a little help (e.g.with buttons) ? ☐ 2
With someone helping you most of the time ? ☐ 3
9

Do you walk indoors ?

Remember - tick one box only

Without help ? ☐ 1
Without any help apart from a frame ? ☐ 2
With one person watching over you ? ☐ 3
With one person helping you ? ☐ 4
With more than one person helping you ? ☐ 5
Not at all ? ☐ 6
Or do you use a wheelchair independently (e.g. round corners) ? ☐ 7
9

Do you move from bed to chair:

Remember - tick one box only

On your own ? ☐ 1
With a little help from one person ? ☐ 2
With a lot of help from one or more people ? ☐ 3
Not at all ? ☐ 4

9

Do you eat food:

Remember - tick one box only

Without any help ? ☐ 1
With help cutting food or spreading butter ? ☐ 2
With more help ? ☐ 3

9

Do you use the toilet or commode:

Remember - tick one box only

Without any help ? ☐ 1
With some help but can do something ? ☐ 2
With quite a lot of help ? ☐ 3

9

Do you brush your hair and teeth, wash your face and shave:

Remember - tick one box only

Without help ? ☐ 1
With help ? ☐ 2

9

Are you incontinent of urine:

Remember - tick one box only

Never ? ☐ 1
Less than once a week ? ☐ 2
Less than once a day ? ☐ 3
More often than once a day ? ☐ 4
Or do you have a catheter managed for you ? ☐ 5

9

Do you soil yourself:

Remember - tick one box only

Never ? ☐ 1
Occasional accident ? ☐ 2
All the time ? ☐ 3
Or do you need someone to give you an enema ? ☐ 4

9

4

MOBILITY

Please answer all the following questions. Read them through carefully before answering. Tick the box to mark the answer.

Only tick one box for each question - like this ✓

Do you walk around outside ?

Remember - tick one box only

- *On your own* ☐ 1
- *On your own with difficulty* ☐ 2
- *With help* ☐ 3
- *No* ☐ 4 9

Do you climb stairs ?

Remember - tick one box only

- *On your own* ☐ 1
- *On your own with difficulty* ☐ 2
- *With help* ☐ 3
- *No* ☐ 4
- *Don't have stairs* ☐ 5 9

Do you get in and out of a car ?

Remember - tick one box only

- *On your own* ☐ 1
- *On your own with difficulty* ☐ 2
- *With help* ☐ 3
- *No* ☐ 4 9

Do you walk over uneven ground outdoors ?

Remember - tick one box only

- On your own ☐ 1
- On your own with difficulty ☐ 2
- With help ☐ 3
- No ☐ 4 9

Do you cross roads ?

Remember - tick one box only

- *On your own* ☐ 1
- *On your own with difficulty* ☐ 2
- *With help* ☐ 3
- *No* ☐ 4 9

Do you travel on public transport ?

Remember - tick one box only

On your own ☐ 1
On your own with difficulty ☐ 2
With help ☐ 3
No ☐ 4
9

IN THE KITCHEN

Do you manage to feed yourself ?

Remember - tick one box only

On your own ☐ 1
On your own with difficulty ☐ 2
With help ☐ 3
No ☐ 4
9

Do you manage to make yourself a hot drink ?

Remember - tick one box only

On your own ☐ 1
On your own with difficulty ☐ 2
With help ☐ 3
No ☐ 4
9

Do you take hot drinks from one room to another ?

Remember - tick one box only

On your own ☐ 1
On your own with difficulty ☐ 2
With help ☐ 3
No ☐ 4
9

Do you do the washing up ?

Remember - tick one box only

On your own ☐ 1
On your own with difficulty ☐ 2
With help ☐ 3
No ☐ 4
9

Do you make yourself a hot snack?

Remember - tick one box only

On your own ☐ 1
On your own with difficulty ☐ 2
With help ☐ 3
No ☐ 4
9

DOMESTIC TASKS

Do you manage your own money when you go out shopping?

Remember - tick one box only

On your own	☐	1
On your own with difficulty	☐	2
With help	☐	3
No	☐	4
		9

Do you wash small items of clothing?

Remember - tick one box only

On your own	☐	1
On your own with difficulty	☐	2
With help	☐	3
No	☐	4
		9

Do you do your own housework?

Remember - tick one box only

On your own	☐	1
On your own with difficulty	☐	2
With help	☐	3
No	☐	4
		9

Do you manage your own shopping?

Remember - tick one box only

On your own	☐	1
On your own with difficulty	☐	2
With help	☐	3
No	☐	4
		9

Do you do a full clothes wash?

Remember - tick one box only

On your own	☐	1
On your own with difficulty	☐	2
With help	☐	3
No	☐	4
		9

LEISURE ACTIVITIES

Do you read newspapers or books?

Remember - tick one box only

On your own	☐	1
On your own with difficulty	☐	2
With help	☐	3
No	☐	4
		9

Do you use the telephone ?

Remember - tick one box only

On your own ☐ 1
On your own with difficulty ☐ 2
With help ☐ 3
No, or don't have one ☐ 4
9

Do you write letters?

Remember - tick one box only

On your own ☐ 1
On your own with difficulty ☐ 2
With help ☐ 3
No ☐ 4
9

Do you go out socially?

Remember - tick one box only

On your own ☐ 1
On your own with difficulty ☐ 2
With help ☐ 3
No ☐ 4
9

Do you manage your own garden ?

Remember - tick one box only

On your own ☐ 1
On your own with difficulty ☐ 2
With help ☐ 3
No, or don't have one ☐ 4
9

Do you drive a car ?

Remember - tick one box only

On your own ☐ 1
On your own with difficulty ☐ 2
With help ☐ 3
No, or don't have one ☐ 4
9

Do you pursue any leisure activities on your own such as reading, stamps, knitting, puzzles ?

Remember - tick one box only

Yes ☐ 1
No ☐ 2
9

Do you attend spectator events (eg theatre, concert, sports)?

Remember - tick one box only

On your own ☐ 1
On your own with difficulty ☐ 2
With help ☐ 3
No ☐ 4
9

Do you participate in games with other people(eg cards, chess, scrabble)?

Remember - tick one box only

Yes ☐ 1
Yes, with help ☐ 2
No ☐ 3
9

Do you participate in home social activities (eg family gathering, party) ?

Remember - tick one box only

Yes ☐ 1
No ☐ 2
9

Do you attend social functions outside of home (eg visiting friends, dining at restaurants) ?

Remember - tick one box only

Yes ☐ 1
No ☐ 2
9

Do you participate in organisational activities (eg church, union, service club, professional ?

Remember - tick one box only

Yes ☐ 1
No ☐ 2
9

MOOD SCALE

Listed below are some questions about mood. Choose the best answer for how you have felt over the ***past week.*** *If you are not sure whether to say yes or no, tick whichever answer you think is* ***most true.***
Please answer every question.

Please answer either "yes" or "no" for ***each question***	Yes	No	
IN THE PAST WEEK			
Are you basically satisfied with your life ?	☐	☐	1 0
Have you dropped many of your activities and interests ?	☐	☐	1 0
Do you feel that your life is empty ?	☐	☐	1 0
Do you often get bored ?	☐	☐	1 0
Are you in good spirits most of the time ?	☐	☐	0 1
Are you afraid that something is going to happen to you ?	☐	☐	0 1
Do you feel happy most of the time ?	☐	☐	0 1
Do you often feel helpless ?	☐	☐	1 0

Please answer either "yes" or "no" for ***each question***	Yes	No	
Do you prefer to stay at home ? (rather than going out and doing new things)	☐	☐	1 0
Do you feel you have more problems with memory than most ?	☐	☐	1 0
Do you think it is wonderful to be alive now ?	☐	☐	0 1
Do you feel pretty worthless the way you are now ?	☐	☐	1 0
Do you feel full of energy ?	☐	☐	0 1
Do you feel that your situation is hopeless ?	☐	☐	1 0
Do you think that most people are better off than you are ?	☐	☐	1 0

☐☐☐

☐

PATIENT SATISFACTION

Please read each statement and tick the answer which is nearest your view. There are no right or wrong answers, it is ***your opinion*** *we are interested in.* ***Please answer every question.***

I have received all the information I want about the causes and nature of my illness.

Strongly agree ☐ *Agree* ☐ *Disagree* ☐ *Strongly disagree* ☐ 1 2 3 4 9

I am happy with the amount of recovery I have made since my illness.

Strongly agree ☐ *Agree* ☐ *Disagree* ☐ *Strongly disagree* ☐ 1 2 3 4 9

Please tick which statement best sums up how satisfied you are with your life in general

About as good as it can be ☐ 1
Good enough, no major complaints ☐ 2
Fair, good enough to manage ☐ 3
Not so good, quality of life leaves much to be desired ☐ 4
Not good at all, poor quality of life ☐ 5
Terrible, my quality of life is very bad ☐ 6
9

If any of the following questions do not apply to you because you do not need the services mentioned, please tick the "does not apply" box.

I am satisfied with the outpatient services provided by the hospital. (eg the day hospital or appointments with doctors or therapists)

Strongly agree ☐ *Agree* ☐ *Disagree* ☐ *Strongly disagree* ☐ *Does not apply* ☐ 1 2 3 4 5 9

I am satisfied with the type of treatment the therapists have given me.

Strongly agree ☐ *Agree* ☐ *Disagree* ☐ *Strongly disagree* ☐ *Does not apply* ☐ 1 2 3 4 5 9

I have had enough therapy.

Strongly agree ☐ *Agree* ☐ *Disagree* ☐ *Strongly disagree* ☐ *Does not apply* ☐ 1 2 3 4 5 9

Please answer every question.

I was given all the information I needed about the allowances or services (eg home help, district nurse, meals on wheels) **I might need after leaving hospital.**

Strongly agree ☐ *Agree* ☐ *Disagree* ☐ *Strongly disagree* ☐ *Does not apply* ☐ 1 2 3 4 5 9

Things were well prepared for my return home

(e.g. aids such as stair rails or wheelchairs had been organised if necessary)

Strongly agree ☐ *Agree* ☐ *Disagree* ☐ *Strongly disagree* ☐ *Does not apply* ☐ 1 2 3 4 5 9

I get all the support I need from services such as meals on wheels, home helps, district nursing etc.

Strongly agree ☐ *Agree* ☐ *Disagree* ☐ *Strongly disagree* ☐ *Does not apply* ☐ 1 2 3 4 5 9

USE OF SERVICES

These are some questions about the services you have received since leaving hospital. They may not apply to you. Please answer them all using a tick to fill in the appropriate box like this : ☑

Did you attend Day Hospital after your discharge ? *Yes* ☐ *No* ☐ 1 2 9

12

Do you attend Day Hospital now ?

Yes ☐ 1
No ☐ 2
9

Have you had any other outpatient rehabilitation at any time (for speech therapy, physiotherapy or occupational therapy) **since leaving the Stroke Unit ?**

Speech Therapy ☐ 1
Physiotherapy ☐ 2
Occupational Therapy ☐ 3
9

Are you having any outpatient rehablitation now ?

Speech Therapy ☐ 1
Physiotherapy ☐ 2
Occupational Therapy ☐ 3
9

Have you received any of the following at any time since leaving the Stroke Unit ?

Health Visitior ☐ 1
District Nurse ☐ 2
Chiropodist ☐ 3
Home Help ☐ 4
Meals on Wheels ☐ 5
Social Worker ☐ 6
9

Have you used any of the following services since leaving the Stroke Unit ?

Crossroads ☐ 1
Day Break ☐ 2
Day Centre ☐ 3
Stroke Club ☐ 4
Volunteer Stroke Scheme ☐ 5
9

Have any of the following come to see you at home since leaving the Stroke Unit ?

Speech Therapy ☐ 1
Physiotherapy ☐ 2
Occupational Therapy ☐ 3
9

Have you had any aids or appliances supplied to your home since leaving the Stroke Unit ?

Bath aids	☐	*Walking aids*	☐
Toilet aids	☐	*Kitchen aids*	☐
Stair rails	☐	*Other aids*	☐

1 4
2 5
3 6
9

Do you recieve any of the following services *now*
(i.e. in the last fortnight) **?**

Health Visitior	☐	*Home Help*	☐
District Nurse	☐	*Meals on Wheels*	☐
Chiropodist	☐	*Social Worker*	☐

1 4
2 5
3 6
9

Do you use any of the following services *now*
(i.e. in the last fortnight) **?**

Crossroads	☐	*Stroke Club*	☐
Day Break	☐	*Volunteer Stroke*	
Day Centre	☐	*Scheme*	☐

1 4
2 5
3 6
9

Since your discharge from the Stroke Unit have you been readmitted to any hospital ? *Yes* ☐ *No* ☐

1
2
9

If **YES**, how many days **in total** have you spent in hospital since your original discharge. ☐☐☐

COST TO PATIENT

These are some questions about how much the stroke has cost you financially. As with all the questions, the information you supply will be treated confidentially. We will not pass any information to any other organisation.

Have you lost any money in the last months as a result of your stroke ? *Yes* ☐ *No* ☐

1
2
9

If so, can you estimate how much ? £ _____

Have you spent any money on aids, appliances or housing adaptations ?

Yes ☐
No ☐

1 2 9

If so, can you estimate how much ? £ _____

Have you had any other costs ?

Yes ☐
No ☐

1 2 9

If so, can you estimate how much ? £ _____

What were they ?

Did you complete this questionnaire ?

By yourself ☐
With help ☐

1 2 9

(give relationship of person who helped you) _____

Thank you for your cooperation

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Dr. Alan Sinclair
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Dr. Dee Jones

AJB/bbc.2204

Dear Carer

This is a brief questionnaire which will enable us to highlight the areas in a carer's life that are most affected when someone close to them has had a stroke.

Your answers will help us to better plan and develop services in the future.

It would be very helpful if you would complete the enclosed questionnaire and return it in the stamped addressed envelope provided.

With many thanks for your help and co-operation.

Yours sincerely

DR ANTONY BAYER

SOUTH GLAMORGAN STROKE OUTCOME PROJECT

Please tick which statement best describes, in your opinion, the quality of life of **the person you are caring for.**

About as good as it can be	☐	1
Good enough, no major complaints	☐	2
Fair, good enough to manage	☐	3
Not so good, quality of life leaves much to be desired	☐	4
Not good at all, poor quality of life	☐	5
Terrible, my quality of life is very bad	☐	6
		9

This question should only be completed if the patient is living at home i.e. not in residential or nursing accommodation.

Please tick which statement best describes your (the carer) quality of life **now.**

About as good as it can be	☐	1
Good enough, no major complaints	☐	2
Fair, good enough to manage	☐	3
Not so good, quality of life leaves much to be desired	☐	4
Not good at all, poor quality of life	☐	5
Terrible, my quality of life is very bad	☐	6
		9

1

Read each question carefully and tick the answer which most applies to you

How difficult do you find it coping with the present situation ?

Not at all ☐ *A little* ☐ *Moderately* ☐ *Quite a lot* ☐ *Continually* ☐

1 2 3 4 5 9

Do you ever feel that you need a break ?

Never ☐ *Rarely* ☐ *Sometimes* ☐ *Frequently* ☐ *Always* ☐

1 2 3 4 5 9

Do you ever get depressed by the situation ?

Not at all ☐ *A little* ☐ *Moderately* ☐ *Quite a lot* ☐ *Continually* ☐

1 2 3 4 5 9

Do you ever feel completely overwhelmed by the situation ?

Never ☐ *Rarely* ☐ *Sometimes* ☐ *Frequently* ☐ *Always* ☐

1 2 3 4 5 9

Has your own health suffered at all ?

Not at all ☐ *A little* ☐ *Moderately* ☐ *Quite a lot* ☐ *Continually* ☐

1 2 3 4 5 9

Do you have family arguments associated with the present situation ?

Never ☐ *Rarely* ☐ *Sometimes* ☐ *Frequently* ☐ *Always* ☐

1 2 3 4 5 9

Do you worry about accidents happening to..... ?

Never ☐ *Rarely* ☐ *Sometimes* ☐ *Frequently* ☐ *Always* ☐

1 2 3 4 5 9

Do you ever feel that there will be no end to the problems ?

Never ☐ *Rarely* ☐ *Sometimes* ☐ *Frequently* ☐ *Always* ☐

1 2 3 4 5 9

Do you find it difficult to get away on holiday ?

Never ☐ *Rarely* ☐ *Sometimes* ☐ *Frequently* ☐ *Always* ☐

1 2 3 4 5 9

How much has your social life been adversely affected ?

Not at all ☐ *A little* ☐ *Moderately* ☐ *Quite a lot* ☐ *Continually* ☐

1 2 3 4 5 9

How much has the household routine been upset ?

Not at all ☐ *A little* ☐ *Moderately* ☐ *Quite a lot* ☐ *Continually* ☐

1 2 3 4 5 9

Is your sleep interrupted by..... ?

Never ☐ *Rarely* ☐ *Sometimes* ☐

Frequently ☐ *Always* ☐

1 2 3 4 5 9

Has your standard of living been reduced ?

Not at all ☐ *A little* ☐ *Moderately* ☐ *Quite a lot* ☐ *Continually* ☐

1 2 3 4 5 9

Do you ever feel embarrassed by..... ?

Never ☐ *Rarely* ☐ *Sometimes* ☐ *Frequently* ☐ *Always* ☐

1 2 3 4 5 9

Are you at all prevented from having visitors ?

Never ☐ *Rarely* ☐ *Sometimes* ☐ *Frequently* ☐ *Always* ☐

1 2 3 4 5 9

Do you ever get cross and angry with..... ?

Never ☐ *Rarely* ☐ *Sometimes* ☐ *Frequently* ☐ *Always* ☐

1 2 3 4 5 9

Do you feel frustrated at times with..... ?

Never ☐ *Rarely* ☐ *Sometimes* ☐ *Frequently* ☐ *Always* ☐

1 2 3 4 5 9

Do you find some behaviours upsetting, such as incontinence, memory problems ?

Never ☐ *Rarely* ☐ *Sometimes* ☐ *Frequently* ☐ *Always* ☐

1 2 3 4 5 9

Do you find it is distressing to find..... has changed so much from his/her former self ?

Not at all ☐ *A little* ☐ *Moderately* ☐ *Quite a lot* ☐ *Continually* ☐

1 2 3 4 5 9

Thank you for your cooperation

APPENDIX D.

Publication.

Poor Functional Status of Stroke Patients After Hospital Discharge: Scope for Intervention?
Corr S, Bayer A. Br J Occup Ther 1992;55(10):383-385.

Poor Functional Status of Stroke Patients after Hospital Discharge: Scope for Intervention?

Susan Corr and Antony Bayer

In a follow-up study of stroke patients discharged from hospital after inpatient rehabilitation in a stroke unit, day-to-day functioning was assessed using the Barthel Index and the Frenchay Activities Index. Levels of dependency recorded at discharge tended to persist or worsen over the subsequent 7 to 12 months and very few patients returned to any domestic, leisure or outdoor activities once they were back in the community. Those in residential care were especially disadvantaged. Contact with health and social services was minimal. The findings suggest that there is considerable need for continuing support and intervention for stroke patients after in-hospital rehabilitation. The occupational therapist would seem potentially well-suited to this role.

Introduction

Most rehabilitation following stroke concentrates on the acute phase and on the recovery of motor function and independence in activities of daily living. The emotional needs and social functioning of the patient and family attract less attention. Professional support and intervention after discharge from hospital is also too often unplanned and haphazard.[1-3]

Many patients and their carers assume long-term disability and poor day-to-day functioning to be an inevitable accompaniment of survival after a stroke. In fact, it is only a minority of patients who survive with significant physical disability[4] and yet few patients ever return to their previous level of everyday activity. Several researchers have confirmed the poor relationship between resumption of social activities and physical recovery[5-7] and instead have highlighted the importance of psychological factors, particularly depression,[8] the age, sex and level of education of the patient[5,9] and the influence, both positive and negative, of carers at home.[10]

The value of occupational therapy in rehabilitation of the stroke patient is well established.[11-13] However, treatment tends to concentrate on maximising functional independence in daily living requirements prior to hospital discharge;[14] instrumental activities of daily living (for example, food preparation, shopping and cooking) and restoration of personal and social activities and of leisure pursuits are given much less attention. Certainly, while trial home visits before hospital discharge are commonplace, regular community follow-up by an occupational therapist after discharge is rare.[3,15]

In order better to determine the potential for continuing rehabilitative input by an occupational therapist after hospital discharge, a series of stroke patients was followed up some months after discharge from a stroke unit.

Methods

The patients studied were consecutive discharges, during a 6-month period, from a 20-bed stroke unit. All had been first admitted to an acute medical or geriatric ward. They were then transferred to the unit after 1-2 weeks because of a need for more intensive inpatient therapy likely to continue for several weeks. Except for two patients from residential homes, all had been previously living independently in the community, with no significant disability or handicap. The ability to perform activities of daily living at the time of hospital discharge was measured by the Barthel Index.[16] A score of greater than 12 (from a maximum score of 20) was regarded as indicating independence.[17]

All patients or their carers were contacted by telephone at least 6 months and not more than 12 months after discharge. Their consent to a home visit by an occupational therapist [SC] was obtained. It was explained that this was primarily to complete some assessments of their recovery after their stroke. The limited time available for the study dictated that the follow-up visit could not be carried out at a fixed time after discharge. However, as most functional recovery occurs within the first 3-6 months after stroke,[18-21] this was thought unlikely to influence the results.

At the visit, the following information was collected: use of health and social services since discharge, Barthel Index and Frenchay Activities Index.[9] The Frenchay Index is a measure of domestic, leisure, work and outside activities which, although not essential to functional independence, reflect a higher level of independence and a more social survival. It concerns those activities that have actually been performed during the previous 3 and 6 months.[22] Specific neurological deficits and perceptual, cognitive or communication problems were not recorded.

Once all the assessments had been completed, the occupational therapist advised the patient and family about any outstanding problems and arranged any necessary referrals for further intervention.

Results

Of the 76 patients discharged during the study period, 27 had died before the follow-up visit. Barthel Index scores at the time of hospital discharge were unavailable for 3 patients, but

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otherwise data collection was complete. The characteristics of the 49 patients who survived, all of whom agreed to be reassessed, are shown in Table 1.

Table 1. Characteristics of stroke patients reassessed at 7-12 months after hospital discharge

Age (years)	
Median	78
Range	41-95
Women (%)	36 (73%)
Time in hospital (days)	
Median	70
Range	13-210
Placements (%)	
Living alone	6 (12%)
With relatives	22 (45%)
Residential/nursing homes	21 (43%)

The number of patients independent in each activity included in the Barthel Index is shown in Table 2. At the time of the follow-up visit, 22 (45%) patients were independent as classified by the Barthel Index score. At hospital discharge, 25 (54%) of the 46 patients with available data had been classified as independent. Of the 21 (43%) patients in residential or nursing homes, 5 were independent at discharge and 3 at follow-up. In the group as a whole, the median Barthel score fell from 13 (range 1-20) at discharge to 11 (range 2-20) at follow-up.

Table 2. The Barthel Index: the number (%) of patients who were independent in each activity at discharge and follow-up.

Activity	Discharge (n=46)	Follow-up (n=49)
Bowel	38(75%)	33(67%)
Bladder	26(53%)	28(57%)
Grooming	38(75%)	29(59%)
Toilet	18(36%)	22(44%)
Feeding	32(65%)	24(49%)
Transfers	21(43%)	24(49%)
Mobility	17(35%)	21(43%)
Dressing	19(38%)	23(47%)
Stairs	17(35%)	15(30%)
Bathing	17(35%)	15(30%)

The poor functional activity of the patients at follow-up was also reflected in their scores on the Frenchay Activities Index (Table 3). Only a minority of patients had carried out any of the listed activities in recent months, with 26 (53%) not participating in any of them. Only 2 (4%) patients were involved in domestic, leisure and outdoor activities. The reasons for patients not carrying out activities (for example, perceptual or cognitive problems) were not determined.

Those living in residential or nursing home care seemed to have particularly poor social functioning. Only 5 (24%) of the 21 patients had taken part in any outside social activity within the previous 3 months; otherwise, none of the patients had carried out any of the other activities listed, although not all the activities may be relevant to those in institutional care.

Despite the poor functional status of most of the patients, their contact with health and social services at the time of follow-up was minimal. Only 11 (22%) were using any type of service. There were 7 (14%) receiving home help, 5 (10%) being visited by a community nurse and 2 (4%) receiving meals on wheels. While 23 (47%) of the patients had attended a day hospital immediately after hospital discharge, only 5 (10%) were still attending 7-12 months later. These patients may have been receiving occupational therapy. However, no patient

Table 3. The Frenchay Activities Index: the number (%) of patients (n=49) who had carried out each activity at any time in the previous 3 or 6 months.

In the last 3 months:		
1.	Preparing main meals	7 (14%)
2.	Washing up	12 (24%)
3.	Washing clothes	7 (14%)
4.	Light housework	9 (18%)
5.	Heavy housework	5 (10%)
6.	Local shopping	8 (16%)
7.	Social occasions	16 (32%)
8.	Walking outside >15 minutes	9 (18%)
9.	Actively pursuing hobby	5 (10%)
10.	Driving car/bus travel	6 (12%)
In the last 6 months:		
11.	Travel outings/car rides	3 (6%)
12.	Gardening	1 (2%)
13.	Household/car maintenance	0
14.	Reading books	10 (20%)
15.	Gainful work	0

was being seen by a community occupational therapist. The number going to a day centre had increased from 2 (4%) at discharge to 5 (10%) at follow-up. No patient was attending any of the five stroke support groups available in the area. Only 4 (19%) of the 21 patients in residential care were in contact with any outside service.

Discussion

The patients in the study were not, of course, typical of all stroke patients. Rather, they were a representative sample of the significant minority who require a period of often prolonged inpatient rehabilitation before their supposed resettlement back into the community.

All the patients studied had survived out of hospital for at least 6 months and it might be assumed that further spontaneous recovery was unlikely. Their poor functional status was therefore likely to be persistent unless active efforts were made to intervene. Those living in institutional care appeared to have particularly poor social functioning, with little contact with everyday life outside and apparently minimal effort made to reintegrate them into the community in any way.

Most of the patients were elderly and this might at first be assumed partly to explain their poor functional outcome. However, nearly all were reportedly fully independent prior to their stroke, although retrospective assessment using formal measures was not attempted. Wade and colleagues,[23] in a study specifically looking at the influence of age upon stroke, found no correlation between age and activities of daily living ability at 6 months or individual recovery. Unfortunately, old age still sometimes limits access to services and inappropriately influences management decisions and it is possible that younger stroke patients may fare better than those in the present study.

Previous audits of stroke services have also found high levels of persistent social and psychiatric morbidity and neglect of planned follow-up, to the detriment of the patient and family.[2,3,24] Even patients whose physical disability has ceased to be a serious obstacle do not necessarily return to a normal social life[5-7] and the need for greater emphasis on psychosocial support in the after-care of stroke patients has been stressed.[25,26] Indeed, without continuing support and rehabilitative intervention after hospital discharge, severely impaired social functioning may be almost inevitable.

It is clearly desirable to improve the long-term outcome of these patients. In hospital, rehabilitation is aimed at maximis-

ing recovery, although the true influence of therapy on long-term outcome following stroke is uncertain. For example, whilst Garraway and colleagues were able to show a benefit of rehabilitation in a stroke unit at time of discharge,[27] at 12-month follow-up[28] the benefits over the less intensively rehabilitated control patients were no longer present. Concentration of rehabilitation services solely on the acute treatment phase therefore seems inadequate and longer-term support continuing after hospital discharge is needed.

Professional responsibility for therapeutic input and active management of stroke patients and their families after discharge is rarely defined. The authors would suggest that the occupational therapist is ideally suited to take on this role, ensuring that individuals reach their maximum level of function and independence in *all* aspects of life, through specific selected occupation.[29] The model of human occupation, for example, has a holistic orientation, viewing humans as occupational beings who can influence their health through participation in occupations.[30]

It is certainly important that any occupational therapy programme established early after the onset of stroke gives full attention to all aspects of the patient's future.[10-12] Social priorities and goals should be encouraged and time allocated for discussion, family education and participation. This programme should not end once the patient leaves hospital; rather, the occupational therapist must remain actively involved, ensuring the re-establishment of previous or the development of new recreational and community interests.

Patients who enter residential care must not be neglected and indeed appear particularly deserving of special attention. It is encouraging that some nursing and residential homes are now employing occupational therapists and it is important that their input makes full use of their skills.

Conclusion

This study shows that the long-term outcome in terms of instrumental activities of daily living and social functioning of many stroke patients is very poor. The scope for continuing intervention after patients have left hospital is therefore substantial. The occupational therapist would seem ideally qualified to meet this challenge. Further studies are needed to determine the impact of continuing occupational therapy input after stroke patients have been discharged from inpatient rehabilitation back into the community.

Acknowledgements

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